

Positive Behaviour Supports for Children



Reaching for the Stars
A Parental Guide to Behaviour Supports

This is a PDF version of the Family Portal of the website Positive Behaviour Supports for Children at:

www.pbsc.info

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of Alberta** 





Positive Behaviour Supports for Children

If you have a child with disabilities you will have experienced both joy and challenges.

Positive Behaviour Supports for Children is designed to enhance your capacity to promote adaptive behaviours and developmental skills, while managing the challenges you face.

The engaging and user-friendly website includes video and interactivities to help you experience the joys of parenting a child with a disability.

This manual is a print friendly version of the content found on the family portal of the Positive Behaviour Supports for Children with Disabilities website.

www.pbsc.info/family/

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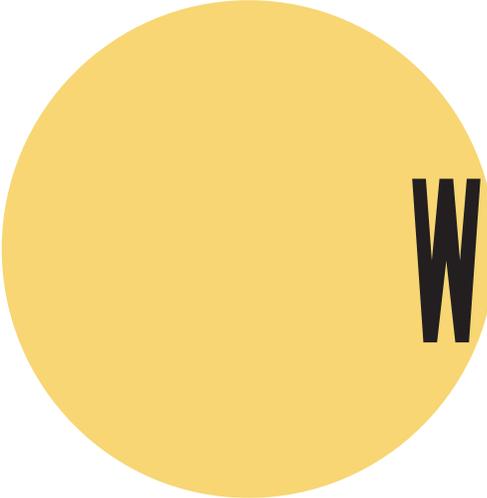
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Module 1: Overview

Unit 1: Overview

Topic 1: Welcome to the PBSC Website

Topic 2: Coping with Stress



Welcome...

The purpose of this website is to provide easily accessible information to parents and caregivers of children who have complex conditions. Children with disabilities such as Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, Down Syndrome, Fragile X, and others, have many strengths as well as challenges. Often, children with a disability can become frustrated by their difficulty in communicating their needs. Some may have difficulty interpreting social cues while others may struggle with activities of daily living. What one child may learn easily through everyday activities may require more focused teaching for a child with a disability. With

help, your child can learn developmental skills, minimizing the challenging behaviours they may have used to meet their needs. Each child is unique, and there is no one approach that will work with every child. It is important to understand how to determine an approach that will work with an individual child. In this website you will learn how to find effective ways to support your child with a disability. This website was developed for parents who have children with disabilities. The website has drawn on their expertise and experience to develop a website that will suit your needs as a parent and as a family.

You will learn:

- How to promote adaptive behaviours, learning and development
- How to understand the function of challenging behaviours
- Strategies to manage and minimize challenging behaviours
- How to work as part of a team
- How to work with your child's school team
- How to plan for important transitions
- How to stay healthy as a parent and as a family

This website is designed to be a resource you can turn to whether you have just ten minutes at a time or several hours. It is also designed to be flexible – you can skip the theory behind some of the strategies if you are already familiar with it, or you can read more about it to increase your understanding.

Here is some information about the website design, content, and how to use it:

This website:

- has a tutorial to orient you to how the site works
- presents information in multiple ways to suit different learning styles. For example, many sections are narrated, but this can be skipped if preferred
- uses video to illustrate specific concepts discussed

Includes a variety of interactivities to help you reflect on how to apply the strategies with your child.

The content:

- covers the age range from preschool to 18 years
- covers the diverse range of skills that your child may have
- is focused on home settings
- includes a range of strategies that may apply to children with mildly challenging behaviours to those children with more severe and complex behaviours
- includes strategies that can be used while supporting children or youth in more natural settings such as home or the community

This website may be used as:

- a comprehensive guide that you can systematically work through
- a place to come when you have a specific question or issue that you would like to explore
- a resource to learn new strategies or review different strategies
- a guide when planning for the needs of your child and family

Note: before you start, be sure to take the website tutorial so that you don't miss any of the features.

Unit 1

Coping with Stress

Stress and strategies to stay emotionally fit

A certain amount of stress can keep us stimulated and lead to growth, but when we are not aware of our stress level or don't know how to manage it in healthy ways, it can be harmful to us physically and mentally. It can also make us less effective in our work. Learning how to manage stress and committing to an emotional fitness plan is just as important as learning how to support children.

Follow the link to the Canadian Mental Health website to read about stress and how it impacts you. Take the "What's your stress index?" Read through the ideas for preventing and coping with stress. Be sure to review the resources and the "stress stoppers". Consider what approaches might work best for you.

The Mayo Clinic has excellent information about stress and self-care. Click on the link and read through the site on stress. Be sure to read the section in Stress basics, on looking for patterns in your coping strategies. Read the strategies for stress relief.



Your Turn

In your journal, write about the following:

- Your reflections on the results of the What's your stress index
- What are your stress triggers?
- What are your coping strategy patterns? How healthy are they?
- What are your telltale signs of increasing stress? (these likely include physical, mental, social & emotional responses)
- Of the five types of coping skills — physical, mental, social, diversions and spiritual — which are you already using?
- What new coping skills will you commit to trying next time you're feeling stressed?

Now, develop an emotional and mental fitness management plan, including strategies to prevent stress and manage it when it occurs.

Follow it to enjoy a rewarding career and a healthy, balanced life!

For more information check out these links online:

Canadian Mental Health Association:

http://www.cmha.ca/bins/content_page.asp?cid=2-28-30&lang=1

The Mayo Clinic:

<http://www.mayoclinic.com/health/stress-management/MY00435>

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Unit 1: Adaptive Behaviour

- Topic 1:** What is reinforcement?
- Topic 2:** Levels of reinforcement
- Topic 3:** How to identify effective reinforcement
- Topic 4:** How to develop a plan and deliver reinforcement
- Topic 5:** How to fade reinforcement
- Topic 6:** Possible difficulties you may face when using reinforcement



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- Topic 1:** Principles of applied behaviour analysis
- Topic 2:** Overall teaching strategies to promote adaptive behaviour
- Topic 3:** Techniques for changing behaviour
- Topic 4:** Discrete trial teaching/ Massed trial approach
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- Topic 6:** Comparing discrete trial teaching and naturalistic teaching
- Topic 7:** Specific techniques: Promoting
- Topic 8:** Specific techniques: Task Analysis
- Topic 9:** Specific techniques: Chaining
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- Topic 1:** Overview
- Topic 2:** What is it?
- Topic 3:** Naturalistic teaching strategies
- Topic 4:** Challenges
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Unit 5: Evaluating Effectiveness

- Topic 1:** Why data collecting is important
- Topic 2:** The different types of data collection systems
- Topic 3:** How to analyze data & use the information to make treatment decisions

Unit 4: Addressing Specific Skill Deficits

- Topic 1:** Introduction
- Topic 2:** Identify treatment goal
- Topic 3:** Applying teaching strategies
- Topic 4:** Communication skills
- Topic 5:** Teaching communication skills:
Requesting
- Topic 6:** Teaching communication skills:
Rejecting
- Topic 7:** Teaching communication skills:
Gaining the attention of others
- Topic 8:** Final thoughts on communication skills
- Topic 9:** Resources for teaching communication skills
- Topic 10:** Social skills
- Topic 11:** Resources for teaching social skills
- Topic 12:** Self-Care & life skills
- Topic 13:** Resources for self-care & life skills
- Topic 14:** Play skills
- Topic 15:** Resources for teaching play skills
- Topic 16:** Cooperation/ coping skills
- Topic 17:** Resources for teaching cooperation/ coping skills
- Topic 18:** Puberty/ Sexuality
- Topic 19:** Resources for teaching puberty/ sexuality

Unit 1

Adaptive Behaviour

What is reinforcement?

Reinforcement is something that we use everyday, often without even realizing it. Telling a co-worker that you like her skirt or telling your child “good job” after he puts his markers away are both examples of using reinforcement. Both of these actions increase the likelihood that the person will repeat the same behaviour; for example, your co-worker may wear that particular skirt again and your child may put his markers away the next time he is finished with them.

There are two types of reinforcement, negative reinforcement and positive reinforcement.

Negative reinforcement is the removal of an unpleasant event immediately following a particular behaviour to increase the likelihood of that behaviour being repeated. For example, a mother continually asks her son, Theo, to make his bed each morning. Then one morning, Theo decides to make his bed before his mother comes into his room. Later when his mother comes in she says nothing and simply smiles at her son. The elimination of the unpleasant stimulus (e.g., his mother’s constant asking) is reinforcing for Theo and will likely increase the chances that he will make his bed again.

Positive reinforcement is the presentation of a positive event immediately following a particular behaviour to increase the likelihood of that behaviour being repeated. For example, Mom calls Jayda’s name. She responds by turning and looking at her mom. She immediately gives Jayda tickles. She enjoys tickles and this will likely increase the chances that Jayda will turn and look the next time her name is called.

For the purpose of this topic, we will focus on the use of positive reinforcement. Positive reinforcement can be used to increase the occurrence of adaptive behaviours and also to increase a child's motivation when learning new skills. Children and youth with developmental disabilities do not learn like their typically developing peers. They often require more incentive to try new things, to practice emerging skills, and to display adaptive behaviours. Reinforcement offers them the incentive they need. Reinforcement can be anything, as long as it is motivating to the child or youth and it increases the behaviour that it follows.

Your Turn

Ben, a four year old boy with Autism, is learning to hang up his coat as part of his morning routine. His father shows him what is expected of him and then encourages him to copy his actions. He hangs up his coat and his dad gives him a “high five”. The next day, Ben hangs up his coat and receives a “high five” immediately after he performs this task. He completes this task every day the following week. Does a “high five” qualify as positive reinforcement for Ben?

Reinforcement versus Bribery

Using reinforcement should not be confused with using bribes. There is an important distinction between using reinforcement and bribery.

Reinforcement	Bribery
<ul style="list-style-type: none"> • This is a proactive strategy • Used as part of a long term plan to modify, or change, current behaviours and/or to motivate your child when teaching new skills. 	<ul style="list-style-type: none"> • This is a reactive strategy that should be avoided. • Usually employed as an act of desperation and may actually increase the frequency of the challenging behaviour.
<ul style="list-style-type: none"> • When using reinforcement, it is helpful to let your child know what you expect him to do and that he will be rewarded for doing it. Using an “if...then” approach --“First sit at table, then slinky”-- is one way to outline this expectation for your child. • Involves planning prior to an activity or event which may result in a challenging behaviour. 	<ul style="list-style-type: none"> • Bribery may involve changing the identified reinforcement. For example, you ask your child to complete a puzzle to earn his slinky. The slinky isn’t motivating to your child, and so you offer a different reinforcement that you had not previously discussed with your child - a remote control car, for example. • Bribery may also involve offering reinforcement after a challenging behaviour has already begun. Offering a reinforcement after a challenging behaviour has already begun can actually increase the likelihood of the challenging behaviour being repeated. Your child learns that certain behaviours -the ones you find challenging- lead to rewards.
<p>Example A parent is waiting in line at a grocery store with his child. The parent says “If you wait quietly you can have a chocolate bar”. The reinforcement was offered before a challenging behaviour arose. The reinforcement was then given after the child was waiting quietly, which may increase the likelihood that the child will repeat this behaviour in the future.</p>	<p>Example A parent is waiting in line at a grocery store with his child. The child begins screaming loudly and the parent says “If you stop screaming you can have a chocolate bar”. The reinforcement was offered after the challenging behaviour began and may actually increase the likelihood that they child will repeat this behaviour in the future.</p>

Levels of Reinforcement

You have learned that positive reinforcement increases the occurrence of the behaviour that it follows. There are two types of positive reinforcement: primary reinforcement and secondary reinforcement.

Primary reinforcements, also called unconditioned reinforcements, are considered to be naturally positive consequences. They are a stimulus or situation considered to be inherently reinforcing for the individual. Individuals do not have to be conditioned or taught to desire them.

Examples of primary reinforcements are food, drinks, and preferred activities.



Secondary reinforcements, also called conditioned reinforcements, have acquired their reinforcing qualities as a result of being paired with something that is naturally reinforcing; -praise may become reinforcing after being paired with candy, for instance. Individuals can be conditioned or taught to desire secondary reinforcements. By pairing new or less reinforcing activities with primary reinforcements, they can become more desirable to the child. This can help to broaden the interests of the child. Also, secondary reinforcements are typically more convenient to use and fit much better into a natural environment -it is much easier to provide a child with praise for completing his worksheet rather than walking across the room to offer him candy.

Positive Reinforcement Hierarchy

Reinforcement can be further organized into a hierarchy. Consider the following hierarchy of reinforcements with the long term goal being to build intrinsic motivation for the child rather than developing a dependency on reinforcement. For example, if you start using primary reinforcements to motivate your child, you would want to begin pairing it with a secondary reinforcement -social, privilege, material -so that the primary reinforcement could eventually be faded. The long term goal is for your child or youth to develop an intrinsic desire (or as close as possible) for completing tasks and performing adaptive behaviours. In the following list, numbers one through four are considered secondary reinforcements and number five is primary reinforcement.

Level 1: Primary (Edible) Reinforcement

Foods and liquids; individuals do not have to be taught to desire them. Since reinforcement is most effective if access to it is restricted (outside of teaching), primary reinforcements should be items that are in addition to the child's basic rights (e.g., foods and liquids required to live). A child or youth should never be deprived of a food or liquid that is considered a basic right.

Examples:

- Treats such as chocolate, chips, pop,
- Anything that appeals to the child or youth

Level 2: Material Reinforcement

Providing tokens, money, stickers, and toys; anything the child or youth might be interested in earning or collecting.

Examples:

- Tokens can be earned and then traded in for watching a favourite TV show
- Money can be earned and then used to buy a new comic book or toy
- Stickers can be earned and then added to a sticker book collection at the end of the day

A token economy is a system that involves earning tokens which are contingent on the child performing a particular skill or displaying a particular behaviour. Once a predetermined number of tokens have been earned, they can then be traded in for a preferred item or activity (e.g., 10 minutes to play a computer game, a chocolate bar). It is these preferred items that are likely to increase behaviour for a particular youth. Money is an example of a

very common token economy system. Individuals work to make money, which they then use to obtain things that are reinforcing to them (e.g., food, new shoes, a new DVD). Tokens often begin as neutral stimuli, but become associated with the reinforcements for which they are exchanged. Over time, tokens themselves can become mildly reinforcing (e.g., conditioned reinforcements), making learning that much more motivating.

Preparation for implementing a token economy includes:

- Selecting the tokens,
- Defining behaviours and rules,
- Selecting reinforcements (what the tokens can be exchanged for), and
- Establishing a ratio of exchange (e.g., 5 tokens earned over the course of the day earns a youth 20 minutes of computer time).

Don't assume a youth will understand how a token economy works. You will likely need to teach him the contingency by giving him a token for a target skill (or adaptive behaviour) and then immediately exchanging it for the reinforcement. As well, you will need to teach him to "store" the token (i.e., onto a board) until it can be exchanged. Visuals to demonstrate what the youth is working for and what he needs to do to earn tokens are often helpful for the successful implementation of a

token economy. Token economy systems can be effective in teaching children and youth to wait for or delay gratification (i.e., the ability to wait for reinforcing items or activities) and can lower the rate at which the child or youth becomes satiated (e.g., gets bored) with a particular form of reinforcement. A Behavioural Aide or other professional can assist you to set up a token economy.

Level 3: Privilege Reinforcement

Activities that the child chooses to engage in when given the choice. These should be in addition to basic privileges.

Examples:

- Going swimming
- Walking to the store to buy a treat
- Watching a favourite movie
- Using the computer

Level 4: Social Reinforcement

Positive attention such as praise, a pat on the back, or conversation.

Examples:

- Giving a child a “high five” for completing his puzzle
- Engaging in a conversation about a youth’s preferred topic, after she has completed her work
- Giving a child tickles for responding to her name
- A smile or nod of approval

When providing praise, there are a number of things to keep in mind:

Be very specific and descriptive (e.g., saying “I like the way you’re colouring in the lines” rather than “good job”). Simply saying “good job” may not be explicit enough for some individuals. Such generalized praise may also result in unintended learning that is hard to reverse. Children and youth may learn with one teaching exposure, so directing the praise to a very specific skill or behaviour is important. For example, if you say “good job” and the child is tapping his toes while colouring, he may connect the toe tapping to the praise.

The praise you provide can change over time. When first used to motivate a youth, praise may emphasize the specific activity or behaviour (e.g., “I like the way you’re sitting and doing your worksheet”, “You did the whole puzzle! Great job”). Later, the praise may change to have more emphasis on effort and affect (e.g., “You’re working so hard”, “You seem to really like this puzzle”).

Some youth may not like to be singled out in front of others. In such circumstances, try whispering when praising a youth or, for youth who can read, hand them a note with words of praise.

Level 5: Intrinsic Reinforcement

Gaining enjoyment or satisfaction from doing something or accomplishing an activity.

Examples:

- Experiencing pride from completing a challenging worksheet
- Experiencing a sense of accomplishment from completing the morning routine at home (e.g., a child gets dressed, eats breakfast, washes her face and hands, and brushes her teeth).

How to Identify Effective Reinforcement

Potential reinforcements need to be identified for your child. Remember, reinforcement can be anything as long as it is motivating to the child and it increases the behaviour that it follows. Reinforcements must be valued and desired by the child. Reinforcements can be highly individualized; what's reinforcing for one child may not be for another. Keep the following in mind when trying to identify effective reinforcements:

Observe what the child or youth gravitates toward. Does he tend to play with cause-effect toys with lights and music or look through books with Disney characters in them? Maybe he enjoys playing by himself or drawing circles with a red marker. Perhaps the 11 year old you work with always brings a computer magazine and sneaks into her backpack to look at it throughout the day. Or maybe she enjoys drawing comic book characters in her book.

Expose the child to a number of different items that could potentially be reinforcing. Until a child has been introduced to novel toys, he may not know that something appeals to him. He may need to be shown how to operate new toys to discover that he likes them. A youth may not know that he enjoys playing card games until he's given the opportunity to learn how to play a few games.

Consider the child's specific interests. If a child likes "Dora" figurines, she may also like other "Dora" related toys (e.g., books, a Play Doh set). If a youth enjoys drawing comic book characters, she may also enjoy looking at comic books.

Complete a "likes and dislikes" questionnaire (Alberta Education, 2003) [p. 183]. This can help generate a list of potential reinforcements to be used at home and school. A checklist of reinforcements may also be helpful (Alberta Education, 2003) [p. 184]. This helps to generate more ideas about potential items or activities that may be reinforcing for the child.

Ask verbal children what they want or have them go through a list of items and activities to help identify what they are interested in. By having a list of items and activities, the child may be reminded of reinforcements that they would not have recalled by themselves. The checklist in the previous example can be a good starting point to help generate more ideas for the child. This can also be done with non-verbal children by having them choose from an array of pictures or actual toys.

Choose. Reinforcements will also have different values. You may like to watch TV but you also like money. Given the choice, you would most likely choose money over watching TV. It is critical to have a range of reinforcements that can be used in a differential manner (i.e., provide "good" reinforcements for "good" behaviours or skills and "extraordinary" reinforcement for "extraordinary" behaviours or skills). That is, when the child gets closer or completely exhibits the desired behaviour or skill, the reinforcement should be very strong.

Your Turn

Think of five things that are motivating for you or someone else you know quite well. Put them in order of least motivating to highly motivating. You will likely see that there are some things that you desire much more than other things. You are also more likely to seek these things out or do something in order to obtain them.

Things to Watch out for:

Limit exposure. When you find a very powerful or effective reinforcement, limit the child's access to it. Reserve such reinforcements for targeting particular behaviours and/or teaching specific skills. This will help the item maintain its reinforcing qualities (e.g., the child will not become bored with it).

Change. Frequently change the reinforcements used to prevent the child from becoming satiated (e.g., if you always give the child a particular treat, after some time the child will become tired of that treat). Reinforcements can be rotated on a regular basis (e.g., once each week or even once each day) so they maintain their reinforcing value longer. You can also limit reinforcements that are based on time (e.g., watching TV, playing a computer game for a specified length of time).

Monitor the chosen reinforcements (e.g., through observation and discussion with others) to ensure that they continue to be reinforcing and the child has not become bored with them. Determine whether a new

reinforcement inventory is necessary. Keeping track of current reinforcements, and ones that were used in the past, may be helpful in generating new ideas when the reinforcement needs to be changed. Remember, the interests of children and youth change (e.g., what was "fun" six months ago may be boring now).

Sometimes reinforcements can be so powerful that a child or youth may want to have that particular item for long periods of time and may even have difficulty giving it back to an adult once their reinforcement time is over. You may even find that some children will engage in challenging behaviours (e.g., tantrums, aggression) when they are required to relinquish a highly preferred reinforcement. It is important to follow through and have the child relinquish the item but it's also important to teach him that he can earn it again in the future. This can be done by initially presenting the reinforcement on a frequent basis just to teach the child that he will get another chance to have it again. For some children and youth you can use a visual (or written)

schedule to show them that reinforcement will be part of their day. It can also be helpful to limit their time with the reinforcement (e.g., five to 10 minutes) if they tend to become fixated on things. However, it is important to strike a balance between limiting their time and also giving them enough time with their reinforcement.

Timing. You may also need to be strategic about when certain reinforcements are used. For example, it is difficult to set up a painting activity 10 minutes before “clean-up” time. You may want to plan an activity like this for when a longer, uninterrupted block of time is available. It may, therefore, be best to choose reinforcements that do not require a lot of preparation and that can easily be cleaned up and/or put away. It may be helpful to create

a visual indicating what is available at a given time or in a given place (e.g., create a reinforcement choice board).

Age Appropriate Choices. When choosing reinforcements, keep in mind that some things may not be appropriate as the child gets older. For example, getting a hug as a reinforcement may be appropriate for a young child; however, once that child is in her teenage years hugging may not be considered appropriate. “Tickles” are fun for many children but you don’t see many youth giving and receiving “tickles” to and from their friends. It is, therefore, helpful to rotate reinforcements on a regular basis so that you have more options available for the child and also to start fading out the reinforcements that are no longer appropriate as children get older (e.g., “tickles”, hugging).

Possible Difficulties When Using Reinforcement

Using positive reinforcement is an effective way to decrease (or weaken) challenging behaviours or to increase (or strengthen) adaptive behaviours or skills. However, there are a number of difficulties you may face when using reinforcement. Let’s take a look of some of these.

It can be difficult to identify effective reinforcements. Reinforcements are highly individualized; what may work for one child will not necessarily work for another. For some children identifying reinforcements can be incredibly difficult. You have to observe very carefully to discover the things children and youth with developmental disabilities find most reinforcing. This may involve exposing them to a number of new toys and activities to help them discover things that they enjoy.

Maintaining control of the reinforcement may prove challenging. Reinforcement is more effective if it is reserved for one particular behaviour that is being targeted. If you

design a reinforcement plan that involves providing chocolate for urinating in the toilet and chocolate is not reserved for this particular behaviour (e.g., the child has a small chocolate bar in his lunch each day), you may find that the child is not motivated by it. Because there are many individuals in the child’s life, it is imperative that they communicate to ensure that approaches are used in a consistent manner by everyone involved and also in all settings (e.g., home, school, field trips into the community).

Unintended reinforcement may also occur. Social reinforcement, in particular, is very difficult to control and may be provided by others in the environment. Additionally,

challenging behaviours may be inadvertently reinforced if attention is motivating for a child and attention is being provided by a number of individuals.

For example, Marcio is working on a puzzle with his father and suddenly throws the puzzle across the room. His father is attempting to reserve his praise and attention for completion of the puzzle. Since Marcio appears to be throwing the puzzle to get out of finishing it, the father decides to refrain from drawing any attention to the puzzle being thrown. However, Marcio's mother walks into the room, picks up the puzzle, takes it over to her son, and says "here sweetie, let's finish your puzzle". The attention Marcio just received from his mother may have reinforced his throwing behaviour and may increase the chances of this occurring again.

Intrinsic motivation can be very difficult to develop for a child or youth. The child who does not develop intrinsic motivation may always require some sort of reinforcement to engage in adaptive behaviours or perform skills. The behaviours or skills may not be performed without the presence of some external reinforcement.

Secondary reinforcement (e.g., material, privilege, social, and intrinsic) must be taught. The reinforcing qualities of such reinforcement need to be learned by the child or youth. You may also have to maintain its reinforcing qualities by occasionally pairing it again with a primary reinforcement to re-establish interest.

Inconsistency in the delivery of reinforcement is unlikely to lead to a positive change in behaviour or skill development. If reinforcement is not provided on a consistent basis, especially in the beginning phase of behaviour/skill acquisition, the child or youth may not develop the target behaviour or skill.

The child or youth may become bored, or satiated, with the chosen reinforcement and the reinforcement, in turn, will no longer be effective in strengthening behaviours. Satiation is very common with edible reinforcements and, although less common with other forms of reinforcement (e.g., activities, social), can occur with all forms of reinforcement.

Satiation can be minimized by:

- Varying the reinforcement used (e.g., rotating through a number of reinforcements on a regular basis),
- Using only enough reinforcement as necessary to maintain the target behaviour (e.g., don't use edibles if social praise or a favourite toy will work),
- Avoiding edibles unless necessary and pairing edibles with other forms of reinforcement so that they can be faded,
- Moving from primary (e.g., edible) reinforcements to secondary reinforcements as soon as possible, and
- Moving from a continuous schedule to an intermittent schedule of reinforcement.



Unit 2

Teaching Strategies

Principles of Applied Behaviour Analysis

Adaptive behaviour is any behaviour that allows the child or youth to adapt or adjust to an environment or situation. Typically, principles of applied behaviour analysis (ABA) are used to support the learning of children with disabilities. The term “applied” means the application of a set of principles or a set of practices. “Behaviour” means a particular action or skill that is observable and measurable. “Analysis” indicates the study of how the application of those practices influences behaviour. ABA techniques support children with a range of disabilities, but are most commonly associated with children who have Autism.

Typically developing children tend to learn a variety of skills without formal instruction. Everyday activities in a home often provide the right conditions for a typically developing child or youth to learn a variety of adaptive skills such as language, social, play and daily living skills. Most children require formal instruction to learn complex skills,

such as reading and mathematics. Children with disabilities often require structured learning to develop the skills that typically developing children seem to learn effortlessly. A variety of strategies exists to help children with disabilities learn these skills. As well as using specific strategies, you can help children and youth with disabilities to learn by using a structured environment. Applied behaviour analysis helps to provide a structure for facilitating learning. We are going to give you information on what ABA is, but if you plan to use ABA, you might need more training.

Applied behavioural analysis uses careful behavioural observation and a variety of techniques to encourage the learning of a particular behaviour. Applied behavioural analysis involves the following:

- An evaluation of the overall skills of the child including their strengths and needs
- Measurement of certain behaviours that you would like to change starting with a baseline
- Choosing objectives and priorities to target
- Planning implementation of strategies to teach and generalize skills
- Ways of measuring that change
- Evaluating the program, including the choice of goals, effectiveness of strategies used

Things to remember when teaching:

- Most behaviour is learned and therefore can be replaced by other behaviours
- Each child is unique and therefore requires an individualized approach
- The behaviours you teach should be adaptive and functional
- Behaviour is influenced by the type of reinforcements or consequences that occur after the behaviour occurs
- Behaviour needs to be observable, or operationally defined
- Altering the child's environment may be required
- Altering the manner in which information is communicated may be required

Overall Teaching Strategies to Promote Adaptive Behaviour

When people hear the term “Applied Behaviour Analysis,” they often think that the term means something very specific. However, the principles of applied behaviour analysis exist in our everyday life and help us modify our behaviour and the behaviour of others without even knowing.

It is important to teach new skills in a systematic manner. The information that you gather including baseline, prioritization of goals, the development of goals and strategies, and planning for the evaluation of those goals, is typically outlined in an individualized program plan

Teaching requires the following:

- **A clear objective** with a definition/description of what you expect to see as an outcome.
- **Consideration of what is developmentally appropriate** for the child or youth when choosing which behaviours to target.
- **Making accommodations** (supports that are permanently in place that the youth depends upon when engaging in certain behaviours) to allow you to address a larger number of skills, given that you are able to target only a limited number of skills during therapy.
- **Considering the overall teaching plan** as well as teaching specific skills. That is, when teaching, it is often beneficial to use task variation. Task variation involves ensuring that variation occurs in the type of activities chosen; for example, preferred versus non-preferred, challenging versus easy, etc. This often helps to reduce the likelihood that challenging behaviours occur, and makes learning more enjoyable for everyone involved.

Here are some things to think about when choosing objectives:

- Select objectives based on an assessment of strengths and needs.
- Success in developing a variety of skills typically requires that the child have some foundation skills.
- The assessment should evaluate and consider the following variables for each child when teaching objectives:
 - Level of motivation—to play, communicate, interact, etc.
 - Ability to imitate—actions, words, etc.
 - Ability to pay attention—how long and to whom, etc.
 - Communication skills—ability to use and understand language

Food for Thought

When you come to work wearing a new shirt and someone tells you that it is a great colour for you, are you more likely to look for that colour again when shopping? You may be more likely to repeat similar behaviours—in this case, shopping for a specific colour—if you receive positive feedback. Similarly, if someone said the shirt made you look frumpy, you might not look for that style again. Positive or negative feedback does not make you do something, but tends to change the likelihood that you will change your behaviour—in this case, how you shop. Factors such as how important that person is in your life may also influence behaviour.

Techniques for Changing Behaviour

Two different theoretical concepts that have formed the foundation for many approaches to changing behaviour follow:

Classical conditioning describes an association between two stimuli and is based on reflexes. The classic example is of Pavlov's dog salivating when a bell rings.

Operant conditioning describes an association that develops between a behaviour and the resulting consequence, a positive or negative outcome, and is the basis for teaching children with special needs.

Operant Conditioning—ABC Learning

There are many formal terms used to describe operant conditioning. Most commonly, operant conditioning is described as ABC learning:

- **A** = the **A**ntecedent, or the activity or event, that immediately precedes the child's behaviour; this is sometimes called a **T**rigger
- **B** = the **B**ehaviour of the child
- **C** = the **C**onsequence that the child experiences as the result of the behaviour



Typically, when you are teaching a specific skill, the antecedent is the instruction—Wash hands. Behaviour is the activity that occurs immediately after the instruction is given. The Consequence follows the behaviour; if it is positive, it will increase the likelihood that the behaviour occurs again when the antecedent occurs, and if it is negative, it will reduce the likelihood that the behaviour will occur again when the antecedent occurs. Recall in the previous section we talked about reinforcement. When a consequence is positive from the child or youth's perspective, it reinforces the behaviour that just occurred.

Here is an example of the ABC's in action:

Jill (mom) pulls a pacifier from Billy's mouth. Billy immediately screams, and Jill pops the pacifier back in. The antecedent is taking the pacifier out. The behaviour is screaming, and the consequence is that Jill returns the pacifier to Billy.

In this situation, if Billy wanted the pacifier back — from his perspective, getting the pacifier back was a positive outcome—the next time he loses the pacifier and wants it back, he is more likely to scream because he may have learned that screaming gets his pacifier back.

The Importance of Timing in the ABC Model

For the ABC model of behaviour to be effective in the teaching of new behaviour, it is important that the antecedent, the behaviour, and the consequence occur within a very short time frame. How strong the association is between the behaviour and the consequence will influence future behaviour.

To be most effective, the Antecedent (trigger) must be followed by the Behaviour, or response, within a few seconds, and the resulting Consequence, or positive reinforcement, should be right at the end of the response, or as quickly thereafter as possible.

Here are some examples:

Vaughn is playing with his friend Min at preschool. Min is sick, and coughs all over the toys that they are playing with. A day later, Vaughn becomes sick with the flu. Because the consequence—getting sick—is so delayed, it is unlikely that this consequence will have any impact on Vaughn choosing to play with Min.

Vaughn is having a snack at preschool. Vaughn offers to give Min some of his raisins, and Min gives him a cookie; Vaughn loves cookies. The next day, when they are at snack, Vaughn immediately offers Min some of his snack. Because Vaughn's behaviour of sharing raisins was reinforced when he got a cookie, he is more likely to share again with Min.

Remember, your opinion about whether a consequence is positive or negative is irrelevant. What is important is the child's perspective and what reinforces one child may not reinforce another.

Additional Considerations When Using ABC

Antecedents (triggers) PREDICT whether the behaviour will occur, but do not guarantee that the behaviour will occur. Prior experience with the consequence, positive or negative, will influence whether the behaviour will occur following that trigger event. As well, consequences may increase or decrease the likelihood that a certain behaviour occurs again, but does not guarantee it.

For a consequence to increase the likelihood that the behaviour will happen again, it must be positive, or reinforced. Every reinforcer is unique, that is, what is reinforcing for me might not be reinforcing for you. This principle is important for teaching new behaviours. It is also important for understanding why a youth engages in inappropriate behaviours, because it's important to identify what is reinforcing the behaviour.

For the most part, we will discuss positive behaviour techniques; that is, things that we can do to increase the occurrence of behaviours that we want to see. Anything that increases a behaviour - makes it occur more frequently or makes it more likely to occur - is termed a reinforcer.

Obviously, if you want to have a positive consequence, you need to think about how to make that positive. There are many ways to reinforce our behaviour. While sometimes the activity itself is reinforcing, often we need to pair that behaviour with something else; for example, no matter how much you love your job, not many people would continue to do it if they were not paid to do it!

Your Turn

In this exercise, identify the following: Antecedent(s), Behaviour(s) and Consequence(s). As well, think about whether the behaviour is more likely to happen in the future when the same antecedent occurs.

Example 1:

Hilda is a five-year-old with Down Syndrome. Her parents are trying to teach her to point to pictures in books. Every morning, they tell her it is reading time. They sit down on the couch, turn off the TV and practice pointing in her ABC book. They start by holding her hand with her finger pointed, and tell her to point to the different pictures in the book. Each time she points, they clap for her. After about five pages, she usually can point to some pictures when instructed to do so. After the book is finished, she gets to have some ice cream, one of her favorite treats.

Example 2:

Phillip is a 12-year-old with a significant cognitive deficit. His parents want him to learn to put on his socks. Each time they take his hands to prompt him to stretch the socks out to pull over his feet, he starts to scream, hit and bite. As soon as he starts to engage in these behaviours, they let go of his hands and put his socks on for him.

Example 3:

Joshua is a four-year-old with Autism. He is learning to use a spoon to eat yogurt, which he loves. His mother tells him to use his spoon, and helps him to grasp the spoonful of yogurt. If he gets the yogurt to his mouth, he gets to eat it. His mother does not spoon feed yogurt to him otherwise.

Things to Consider

The models presented in the following section are not mutually exclusive— all use applied behaviour analysis as a principle for teaching; how the principles are applied is different. The models can range from highly structured teaching to purely naturalistic teaching.

Most structured models support the generalization of skills into naturalistic set-

tings, and most naturalistic models will add some structure to the natural setting. You might choose to teach different skills using different models. That is, you may elect to teach some skills in a very structured manner, and find it more effective to teach other skills in a naturalistic manner.

Choosing a Teaching Strategy

You must consider the child's strengths and needs when choosing different teaching strategies:

- The child's learning style— visual, auditory, tactile, etc.
- Whether the child has a tendency to become dependent on prompting by an adult
- Whether or not the child can and will imitate
- The child's developmental level— assessing the child's skills are across domains, including his communication skills
- What motivates the child—what will reinforce learning

Organizing the Teaching Environment

Once you have considered the child's learning style, consider the teaching environment, such as the layout of the room, how to individualize work areas, and how to transition from one area to another. The learning environment may influence the child's ability to learn and generalize across environments. Many children with developmental disabilities

do not automatically transfer or generalize the skills learned in one setting or with one person to other settings or other people. To improve a child's ability to learn, you may choose to make environmental adaptations. These may be short-term in nature, lasting for only for a certain period, or permanently made for the child.

Examples of environmental adaptations include the following:

Removing/reducing distractions

Examples: taking down pictures, closing windows, sitting at the front during a group activity.

Changing the quality/quantity of sensory input

Examples: dimming the lights, speaking in a quiet voice, wearing headphones

Incorporating calming activities into the daily routine

Example: sitting in a quiet area

Making physical changes to the environment

Examples: removing barriers, using different kinds of lighting

Providing a clear schedule

Example: using a visual schedule that pictorially represents the expectations for an activity

Scheduling breaks in between more challenging tasks

Food for Thought

Although we talk about these strategies in the context of teaching children with developmental disabilities, they are also techniques that typical adults commonly use on a day to day basis to support their own ability to work and complete complex tasks. Would you be able to concentrate on reading a book at a hockey game? A change of environment, such as reading in a library or quiet room, is the best option to increase your ability to focus. However, if you had to read a book at a hockey game, you might choose to wear a set of headphones to cut down on the noise and wear a hat with a brim to reduce the visual input around you.

Communication Techniques that Increase Cooperation

The following tips may improve success with teaching and increasing cooperation: Don't ask a question when you are really giving an instruction: It seems more polite to give a choice about something, but when you are teaching, be clear what your expectations are. Make a statement about what will happen next, e.g., "It's time to do a puzzle", instead of asking a question, e.g., "Do you want to do a puzzle?"

Make sure that you are close enough to the child or youth when giving an instruction:

Remember, how quickly the behaviour follows the instruction, and how quickly the reinforcement/consequence follows the behaviour, are important for learning. If you are not close enough to prompt and reinforce, your teaching may not be effective.

Keep your voice natural and neutral:

Get the child's attention first rather than using a loud or singsong voice to get attention when issuing an instruction.

Remember that you are always modeling with your own behaviour, so be sure to be a positive model.

Children require processing time when you give an instruction:

While we want to make sure that we teach children to respond in a timely manner, knowing how long it takes a child to process and respond to instructions is important. You want to prompt in a timely manner. However, you

don't want to interrupt the child's processing, nor do you want to wait too long if their attention span is limited.

Provide instructions at a level appropriate for the child:

Some children can manage one instruction at a time, while others can process and remember multi-step instructions. Individualize instructions according to the child's skills.

Say what you want, rather than what you don't want:

Give a positive instruction, such as, "Hands on lap," rather than a negative one like, "Don't grab." This helps to focus on the appropriate behaviour, and reduces the likelihood that the child will focus on negative language or the undesirable behaviour and repeats it back to you.



Unit 3

Naturalistic Teaching

Overview of Naturalistic Teaching

Naturalistic teaching is child-directed and occurs in naturalistic settings, rather than structured adult-directed interventions. The aim is to help teach your child how to learn in his natural environments in the same way that a typically developing child learns. Certain skills are taught most effectively within the natural environment, such as play skills, social skills, and social language skills). The focus is to teach your child to interact within their environment in a way that is functional, meaningful and independent.

Focus is on your child's strengths and interests, and the activities that would be expected or typical for a child. As much as possible, use reinforcers directly related to the setting and/or activity as opposed to reinforcement that does not necessarily relate to the activity.

Naturalistic teaching also focuses on teaching across a variety of environments, people, materials and instructions rather than generalizing step by step as is common with discrete trial teaching. Naturalistic teaching typically uses a variety of instructions, stimuli, materials, and responses to teach specific concepts. It is effective for teaching spontaneous responses that occur across environments and for developing functional skills.

An example:

Abdullah, a six-year-old with Autism, is playing in his living room with his mother. Abdullah finds a shape sorter while digging in his toy box. Because he has an objective to identify colours and shapes, his mother holds up a red triangle and asks Abdullah what colour it is. Abdullah says, “Red.” She responds back, “Red triangle,” high five’s with him, and gives him the red triangle. She continues asking Abdullah colour and shape questions until the shape sorter activity is completed. He then grabs a book, and sits next to you. As they flip through the book, Abdullah’s mother

points to different pictures, asking him about the colours of items. Because he also has an objective to identify animals, she asks him animal questions. After the book is finished, his mother asks him to put the book and shape sorter away because Abdullah has an objective to put away his toys. They go to the kitchen, get out a snack, and work on one of his utensil objectives to eat with a spoon. His mother cuts his celery into different lengths, and works on having him identify which ones are long and short; Abdullah is also working on recognizing lengths.

Your Turn

Consider which skills you currently teach using a naturalistic teaching method. Are there other skills that you could teach using this method?

When you are teaching in naturalistic settings, there is less concern that your child will learn the wrong thing. That is because you do not structure the environment the way you would with discrete trial teaching because the environment itself reflects random exposure to different stimuli.

However, when teaching in naturalistic settings, it is important to change the stimuli in the environment, how different stimuli are used in the environments and/or the environments themselves, in order that your child generalizes across stimuli and settings. You should ensure your child is exposed to a variety of environments, materials, instructions, etc, during the teaching phase to increase the likelihood of generalization.

In practice, a particular teaching model rarely operates without aspects of other models. For instance, discrete trial teaching usually involves generalizing skills into a more natural environment with less structure, and naturalistic teaching will involve some structure to the environment. Generally, when specific objectives are targeted, you will select materials that support learning of those objectives regardless of which model is being used to teach a skill i.e., you can’t teach ball skills without a ball.

What is it?

The essence of naturalistic practice involves weaving our teaching and your child's learning opportunities into a typical day. We have all heard of teachable moments: using the things that happen in a child's day to help him learn. It looks and sounds simple; however, it takes some thinking, planning and effort to do it well.

Naturalistic teaching is grounded in the idea that play is your child's natural way of learning and that play and everyday activities can be used purposely to teach a range of skills including personal care, community skills and interactions. Many of these skills are much easier to teach in the natural environment as simulating them can be difficult.

Features

Naturalistic teaching occurs through your child's day at various times and in different contexts. It is particularly valuable to apply naturalistic teaching when your child is involved in familiar routines such as play, mealtimes, bedtimes, transitions and outdoor play. The techniques used are similar to those used in structured environments, including reinforcement, prompting, shaping and others, but may also use additional techniques such as modeling, commenting, etc. Repetition for developing skills can be built into the natural routines of daily life. With a naturalistic approach, teaching can occur across all settings, including home, community and school — not just during therapy sessions.

When using naturalistic teaching, consider the following:

- Familiar activities are more likely to be functional and meaningful to your child.
- Activities should follow your child's lead and interest.
- You should respond to your child's interest as well as initiate activities.
- Use functional reinforcers that are indicated by your child's requests and attention.
- Allow for natural consequences.
- Activities chosen should be appropriate to your child's level of development. For example, if your 6-year-old is not able to read, choosing games for age 6 and up that rely on reading are not appropriate.
- Naturalistic teaching should occur during familiar routines (e.g., play, mealtimes, bedtimes, transitions, outdoor play).
- Parents, siblings, familiar adults and peers can be coached or receive training to participate in naturalistic teaching.

Naturalistic Teaching Strategies

1. Routines

Routines are an excellent way for children to learn. They learn best when engaged in meaningful experiences that provide a realistic context for their activities and language. This makes it easier for them to apply what they have learned.

In addition, other children and siblings can typically be included easily in these routines. These routines (sometimes referred to as Joint Action Routines) include three main types:

- Routines with a specific end product (e.g., cooking);
- cooperative turn-taking games or songs; or
- routines around daily living, such as going to bed.

Tips when engaging in routines:

- Plan and follow through with routines slowly. It may seem easy for you, but your child may need time and practice to understand the multitude of steps involved.
- Start with routines that your child is interested in.
- Use supports such as prompts, modeling and pictures as needed to encourage your child's understanding. Withdraw these prompts as your child develops her skills.
- Provide ongoing structure and repetition until the routine is established. As the routine is mastered, introduce variation but keep the essence of the activity the same.
- Use a clear, consistent signal to mark the beginning and end of the routine (e.g., "all done" or "let's play Dairy Queen").

2. Balanced Turn Taking

One skill that is important for children to learn is to take turns. This is critical for communication and social skill development. To this end, we need to help children initially establish that having a partner can be fun. Secondly, children need to understand that there are two roles in communication: a speaker and a listener. There are often two roles in play as well (e.g., hide and seek).

For young or cognitively impaired children, you might try playing with cars beside a child or gently interrupting play to include yourself in a turn. For older or higher language children, turn taking may involve a shared conversation about an event, such as a birthday party your child just attended. A partner may then interrupt with organizing questions (e.g., Who was there? What did you do first?) to help your child develop the idea of taking turns in the conversation.

3. Waiting

Waiting is an essential skill when working with children (and adults). Learning the skill of waiting while keeping up the pace of the activity may, arguably, be one of the hardest skills for aides and therapists to learn. Stop right now and set your watch for one minute. Say nothing for one full minute. A minute is a long time, isn't it?

Many of our children have difficulty listening and following directions. If given more time to process the language and plan their action in response, whether it is speech or a motor movement, a child may be able to follow through more successfully.

- Remember to look expectantly when waiting to show a child non-verbally that you are waiting for her turn.
- Stay at their level, maintain eye contact and smile expectantly.

4. Following a Child's Lead

We all have favourite activities that make us feel happy and relaxed. Think for a moment about some of your favourite activities. It is the same for your child. They have likes and dislikes just as we do. What are some of your child's favourite?

One of the best ways to learn about children is through observation. Watch what your child does when you are not around. What does she like to do when she is alone, or playing with other siblings? What does she do in different environments? For example, if your child likes to play with his Thomas the Tank trains, you could use Thomas to work on goals, such as developing language, cognitive, social or play skills.

5. Match – Model – More

One way to support your child's language is to match your child's language level and to gently increase. If your child uses two-word sentences, then you should start with two-word sentences as well. You can add one word to model and expand on the language they are currently using. For example, if your child says, "More cookie," you could say, "Want more cookie?" or "I want more cookie." By modeling the language at one level above your child's, you will help her improve her language level.

Children's use of simple phrases or repeated language can be a key to opening the door to social communication. Use these phrases to support your child in learning to talk and to build on what your child knows. Be sure to model language that would be appropriate in the situation. Instead of "Say, bye Daddy," try to model what would be appropriate: "Bye Daddy." This is a much more appropriate language model for all children.

6. Act Silly / Creatively Stupid

By setting up environments for the unexpected, you will elicit a response from your child. For example, pretend not to know the name of something, or not be able to find something hiding in plain view. Your child may want to help and/or like taking on the role of teacher.

7. Novelty

Since children are often intrigued by new toys and activities, carefully adding novelty may engage them and provide an opportunity to learn or teach something new. For children with disabilities, introducing novelty within the context of a familiar routine or activity is likely best. For example, add a new action to a familiar song. Or show a new way to enter a building within a familiar routine. Make sure the novelty is not too different from what they are expecting.

8. Violation of Expectations

Leaving out or changing a step in a well-known routine is called 'violating expectations.' For example, starting to draw without a crayon, or playing a game without the die. This can be funny for children, and can provide the chance for them to communicate and problem solve. It also tells us about their discrimination and memory. It gives us the opportunity to shape their responses into functional behaviour.

9. Piece by Piece

Using activities with several pieces can increase the opportunity for your child to respond in the desired way. For example, have your child request or correctly label each puzzle piece, or each marker used when drawing a picture. This can be used when children use paint, glue, paper, blocks, and so on, or during snack time with a variety of food types. It is also important to watch for too many disruptions when using this strategy, as continual requesting can interfere with your child's engagement in the activity.

10. Assistance

Using materials or activities in which adult assistance is required also provides naturalistic learning opportunities. To get materials or complete an activity, your child will need help from an adult or peer. This can help develop a variety of skills. For example, giving a child a snack in a container that she can't open gives the chance for her to ask for help. Once it is partially opened, she can develop her hand and finger strength by completely opening the container and getting the snack.

11. Interruption or Delay

This requires that the adult stop your child within a sequenced routine so your child needs to use language to ask for what he wants or needs to complete the task. For example, stopping your child from getting the towel after handwashing, and either pausing or asking "What do you want?" enables your child to ask for the towel.

12. Use Non-verbal Supports and Gestures

Communication is more than the words we use, it also includes the way we say words, the facial expressions we use, the way we hold our body and the hand gestures we use to accompany our communication. Help your child understand by using gestures and body language when you are talking and listening. You can use your language to describe what you are doing (e.g., "I am looking at my watch because I need to go soon").

- Play games with gestures to help your child use and understand pointing. Start with bigger gestures and fine tune gestures as he learns to follow your point.
- Teach emotions along with facial expressions. Be sure to use exaggerated expressions first and then gradually become more sophisticated and graded with your facial expressions.
- Play games without language sometimes. You can call it a “mirror game,” where your child tries to follow your body movements. Be sure to switch roles so your child can lead as well.

13. Watch Use of Questions

Where were you? What were you doing? Did you see Grandma? Who else was there? These are questions we often ask as we try to draw out language from children. Many parents have experienced the common refrain of “nothing” when asking questions of their children.

For children with disabilities, commenting within the situation may give your child a more appropriate model. For example, while reading a book, you could label items within the book while pointing to a picture and then point and stop, waiting for your child to respond. This is a more natural interaction rather than saying “What’s this?” during a book reading activity.

Some children become incessant questioners. They may often ask the same question or ask many questions without apparently listening to the answer to the question. One way to support children is to write down or visualize the answer to the question in one area of the house. You then could refer your child to the fridge as he keeps asking the questions. This may help your child learn to follow cues in the environment.

14. Visual Supports

Many of us use a daytimer to keep track of our appointments and events during the day. This can be known as a high-level visual support system. Many children with disabilities use many different levels of visual systems. These systems can support their understanding and, in some cases, improve their use of expressive and receptive language.

- Visuals should also be used to support a child’s understanding of an activity.
For example, a common visual schedule may include a hand washing routine.
- Point to signs in the environment to help your child understand that signs have meaning.
For example, you could ask her to find the stop signs, McDonald’s signs, Walmart, etc.
- During a game, using a visual plan may include ‘Sammy’s turn’ and ‘Kara’s turn’. Playing at the park may include getting dressed, walking or running to the park, choosing activities when at the park, etc.

Challenges with Naturalistic Teaching

The advantages of naturalistic teaching strategies have been described in the previous sections. It is important to also consider the challenges involved in this approach. This will ensure that we are addressing them, thus improving the quality of our intervention.

The challenges include:

- **Remaining goal focused**

When embedding goals in natural routines, goals must be kept in mind, as simply following the routine can become the focus. It requires simultaneous concentration on the routine and goal so that techniques can be incorporated into the routine.

- **Supporting other family members and caregivers**

It can be challenging to grasp the idea of how to use daily routines to teach skills. . You may need to request teaching and support for yourself, other family members, and other caregivers. Your Aide may be able to help you develop this skill.

- **Disorganization**

Naturalistic teaching requires preparation and planning to structure settings and activities for maximum benefit. Lack of planning and organization ahead of time limits the effectiveness of this form of teaching. Think about the goals you can work on during your planned activities, and what materials are needed to provide the learning opportunities.

Naturalistic Teaching with Younger Children

Communication:

Communication skills are essential for all children (and adults). Communication skills are typically broken down into two broad areas: speech and language. It is important to consider goals in both areas.

Speech:

Working on a child's sounds is an area that may require both child- and adult-centred practice. For example, if a child is working on articulating a particular sound, such as /f/, he must first be able to make the sound in isolation before practicing in a naturalistic setting. Thus, this goal may begin with more adult-directed practice at a table. Initial goals may include making the 'bunny' sound by putting the top teeth on the lower lip and blowing. Practice activities at this level may need to be adult directed in order to provide the teaching needed to encourage production of this sound.

Once this sound is mastered, you may work towards functional words as soon as possible.

These words could then be incorporated into more naturalistic activities. For example, while reading "Jack and the Beanstalk," your child can add in the "Fee Fi Fo Fum". Although still adult-directed, you are moving to a more naturalistic activity. Other activities could then be incorporated such as choosing a fork or a spoon to eat pasta or naming the utensils when setting the table for dinner.

An adult or a play partner may support the language-delayed child by making activity-related comments and modeling language responses appropriate to your child's interest within play (Handbook of Developmental Disabilities).

Language:

Language activities lend themselves to naturalistic, child-centred practice. For example, if a child is working on requesting items, his environment can be set up to encourage requesting. Johnny Abu really likes to eat Cheerios for a snack, so his dad puts the box of Cheerios on a high shelf in plain view for him to request. Small amounts of Cheerios can be shared to ensure requesting within this activity. Similarly, if your child is working on asking questions, you can set up the environment to encourage her to ask questions. For example, hide a small object in your child's shoe. As she is putting on her shoe, she could ask "What is it?" or "What is this?"

Suma loves the trampoline. Jumping on the trampoline is a good way to facilitate interaction and work on concepts of high and low. As she is jumping on the trampoline, incorporate 'high' jumps and 'low' jumps. Other soft items such as dolls and nerf toys could also be used to jump high and low on the trampoline.

Bashir is working on developing the ability to describe activities and objects. Knowing he enjoys cars and animals, his dad hides some of each in a bag to create a describing game. As he reaches in and selects a toy, he describes the toy and then gives it to him. As he develops beginning descriptive skills, his dad asks him, "Do I have a car or a horse?" He builds up to more difficult descriptions, saying "It is brown, you ride it, and it lives on a farm."

Augmentative communication (reporter, 2007 vol 13; 1): If your child uses a communication system, a game could be practiced at home that could then be adapted for use with a peer at school or preschool. During a game such as Don't Break the Ice, you could teach (within an adult-directed format) the rules of the game and language associated with playing the game. This activity could then be played with peers at school to encourage language development and also to enhance peer interactions.

Social:

Many social skills can be taught with a naturalistic approach. Often eye contact and play are two areas of concern. For example, Dawit is working on making eye contact, (sometimes referred to as joint attention), and likes balloons. His mom blows up a balloon near his face, releases the air, and then slowly blows up the balloon again, while waiting for him to make eye contact. It is important to encourage brief eye contact as it will typically increase as your child relaxes and becomes more comfortable. Be sure to model natural eye contact, not prolonged eye contact.

Pretend play: Play is an excellent time to use naturalistic approaches to teaching. A

wide range of skills can be taught within the context of play. Social skills like taking turns, communication skills like requesting, life skills like cleaning up, etc. can all be taught through play. To do this effectively you need to understand play and the toys that are being used. You must also plan for opportunities to develop skills in the context of play. For example, riding a tricycle could be a time to develop communication skills (e.g., stop please), cognitive skills (e.g., red light, green light, left or right), gross motor skills (e.g., balance, pedaling) and social skills (e.g., taking turns, lining up).

Your Turn

Calin is pretending to ride on a school bus. In this play activity list the developmental skills could be practiced in this play activity? Could be a matching activity, or start with examples and have user finish? Should be able to include play skills, cognitive, language, fine motor, gross motor and social and life skills (paying fare, getting transfer, etc.) We see a stop sign, what do we do? Ok, the light turned green, let's keep going. Go around the corner...etc.

Peers and siblings can be used as teaching partners within play. You can teach them to wait for a request before giving the desired object to your child and praise her for correct responses.

Cognitive:

Book reading activities (Hanan Sept 2003): During book reading activities, parents and caregivers' expectations often include listening, attending and responding to questions related to the book's content. However, it has been found that these kinds of activities can lead to a decrease in child utterances and word combinations compared to other activities

such as a playdoh activity (Sept 2003). Therefore it is important to remember when you are reading to ensure that your child has plenty of opportunities to interact and use language skills where possible. Remember that your child may also develop other skills such as fine motor skills when turning pages or social skills to sit and maintain attention or language skills

when they hear words and associate them with pictures.

Sharing book reading or making it a more conversational activity can enhance the activity in different ways for children. To enhance the naturalistic reading aspect, try reading slower, allowing time for your child to comment and ask questions. Repetitive reading of books has been shown to foster enrichment for younger children with learning delays (Hanan).

Using songs and action songs (finger plays) can help children learn concepts and

ideas. Start with a consistent song with actions (see Joint Action Routines) and then start to change expectations (e.g., child fills in the word or action) or change the song by adding new words, names, or actions. For example, you could make a visual support with pictures for your child to request one of four songs. Once your child has picked a song, you can sing the song and leave the final word off (e.g., The wheels on the bus go __ , and look expectantly).

Life Skills:

Home routines are a good way for your child to understand meaning in context. Cooking is a classic activity that can be used to practice skills. From stirring to measuring to vocabulary, cooking encompasses many skills to support your child's development.

- Work within the home environment to ensure supports within activities. Using language within as many activities as possible can help your child understand.
For example, if he is working on matching, talk about how socks go together (e.g., These two socks are the same because they are red and small).
- You may bring along picture supports needed for asking to go to bathroom while out in the community.
- Show visual symbols that may be found in the community (e.g., lights, crosswalk signs, etc.).
- Use a variety of verbs to support learning when on a walk (e.g., jumping, walking, running, skipping, etc.).

Community:

Playing at the park. For example, teach your child to stand near another child and wait, or model playing in the sand beside another child. If the other child ignores you and your child, you may want initiate interaction by smiling when the child acknowledges you or add a comment, “I am building a castle for my truck.” By modeling these strategies, we are teaching a more appropriate way for your child to interact that is also based on how children play with each other.

Waiting for appointments can be difficult for children with special needs. If your child has difficulty with going to the doctor, for example, you might start with short, frequent visits that do not involve an actual appointment, and that end with a reward such as

a preferred activity or a favourite toy. Breaking down the steps needed to complete the doctor’s visit may help your child follow through on the appointment over time.

Going grocery shopping can also be a family errand that children with disabilities find challenging. You could bring a favourite item to help him maintain control in the situation. For example, if your child enjoys trains, he could play with a train as long as he stays seated in the cart. Short visits followed by visits of increasing length may help your child learn to complete the task and self-regulate during these activities. Providing an incentive for completion may also be helpful.

Naturalistic Teaching with Older Children and Youth

1. Communication

- Have your child explain the rules of a familiar game to you, as if you are playing it for the first time.
- Have your child describe where to find a certain object.
- Have your child describe what she did during her day. Ask probing questions (e.g., What happened next? What color was her dress? Describe the food.).
- Have ‘trouble’ performing a task, locating an object, etc. so that your child has to add details to his instructions to you.

2. Socialization

- Coach your child regarding conversational topics prior to arranging an activity with a peer, and provide a small visual support with possible topics or questions.
- Practice possible scripts for phone conversations with a peer to invite them over.
- Play games; participate in activities with siblings.

3. Cognitive Skills

- Prompt your child to use problem-solving strategies when encountering obstacles in daily routines. For example: there are not enough clean forks to set the table for the family meal; your child does not have the necessary material to complete homework; or he does not have his friend's phone number.
- Your child wants to purchase a certain item, and needs to determine whether she has enough money to do so.
- Your child needs to find out who in his family wants hot dogs and who wants hamburgers for dinner so his father can cook the correct quantity.

4. Life Skill Development

- Your child would like to attend a movie with a friend and needs to find out what time it starts.
- Your child is learning to do her own laundry and needs to learn how to sort her dirty laundry.

5. Community-based Skills

- Your child needs to practice the skills needed for taking a bus (e.g., reading signs, telling time, having bus fare, socializing appropriately).
- Your child needs to learn how to use a bank machine.

6. Communication Temptations

Wetherby & Prizant (1989) talk about setting up activities that will increase your child's motivation to communicate. They refer to this strategy as "Communication Temptations". This might include trying some of the following:

1. Eat a desired food item in front of the child without offering any to the child.
2. Activate a wind-up toy, let it deactivate, and hand it to your child.
3. Look through a few books with your child until he indicates that he would like to read one.
4. Initiate a familiar game with your child until your child expresses pleasure, then stop the game and wait for your child to request that it continue.
5. Open a jar of bubbles, then close the jar tightly. Hand the closed jar to your child.
6. Blow up a balloon and slowly deflate it. Hand the deflated balloon to your child or hold the deflated balloon up to your mouth and wait.
7. Hold a food item or toy that your child dislikes near your child to offer it.

8. While your child is watching, place a desired food item or toy in a clear container that she cannot open. Put the container in front of your child and wait.
9. Roll a ball to your child. After your child returns the ball three times, switch the toy to something else on wheels and wait for your child to return it.
10. Wave and say “bye-bye” to a toy upon removing it from the play area. Repeat this for a second and third toy, and do nothing when removing a fourth toy.
11. Bring out a toy animal and have it greet your child. Repeat this for a second and third time, but do nothing when bringing out the animal for the fourth time.
12. Put an object that makes noise in an opaque bag and shake the bag. Hold up the bag and wait.
13. Engage your child in an activity of interest that necessitates the use of an object for completion (e.g., crayon for drawing, spoon for eating, or wand for blowing bubbles). Have a third person come over and take the object, go sit on the distant side of the room, while holding it within your child’s sight and wait.



Unit 4

Addressing Specific Skill Deficits

Introduction

The skills displayed by children and youth with developmental disabilities often differ from those displayed by typically developing peers. Deficits or delays are often observed in the following areas:

- Motor skills
- Cognitive abilities
- Communication skills
- Socialization skills
- Self-care abilities
- Play skills

It is also important to remember that typically developing children tend to learn a number of critical skills, such as turn taking, paying attention to the person that is speaking, and functional play, without formal instruction. However, children with disabilities often require systematic and intensive teaching to master the skills that other children learn through observation, interaction and imitation.

As a parent one of your most important roles is to assist your child to develop their abilities.

Examples follow:

- Expanding their current skill sets
- Living up to their potential
- Functioning as independently as possible

Teaching is also essential to reduce or eliminate a challenging behaviour. Challenging behaviours often serve a specific purpose or function. Sometimes the child lacks the skill to meet his need in a more appropriate manner, so engages in a challenging behaviour in order to have his need met. Therefore, we need to teach appropriate ways to meet those needs.. Just as a reminder, here is a list of possible reasons why a child may display an undesirable behaviour such as hitting or screaming:

- To communicate
- To avoid a task or activity they do not enjoy or find difficult
- To gain access to something they want
- To seek out sensory stimulation
- To gain attention from others
- Out of boredom
- Out of habit

Food for Thought

Did you notice that “annoying/upsetting others” was not listed as a common reason? Although we often make this assumption, it is generally incorrect. In most situations, the child is simply trying to get their point across, cope with a difficult situation, or meet their needs using the skills that they have. Keep in mind that we often comment on and attend to behaviours that we find annoying. Although we would like to see annoying behaviours reduced or eliminated, paying attention to them may actually strengthen them.

Children and youth display challenging behaviours for a REASON. However, the reason or purpose is often not immediately obvious to us. The behaviours that we tend to consider the most challenging—hitting, screaming, spitting, destruction, tantrums—are often a direct result of the child’s disability and/or skill deficits. Let’s look at some common examples:

Using behaviour to protest or reject

Sarah is a preschooler with limited fine motor skills. She is asked to engage in a colouring activity. When the materials are set in front of her she throws them and starts crying. In this example, it is possible that Sarah is using her throwing and screaming behaviour to indicate that she does not want to participate in the presented task.

Using behaviour to gain attention

A parent is talking on the telephone while her son is watching a DVD. The boy is nonverbal. When the movie ends, he gets up from the couch and hits his younger sibling. In this situation, it is possible the child is using his behaviour (hitting) to try to get his mother to end her phone call.

Using behaviour to seek out sensory stimulation

During a break at a work placement, a youth with Autistic Spectrum Disorder (ASD) takes her water bottle, removes the lid and slowly pours the water on the table. She stares intently at the water as it drips onto the floor. In this case, it seems likely that the girl may have dumped the water because she enjoys watching the dripping motion. Individuals with ASD often display unusual sensory interests.

Using behaviour to combat boredom

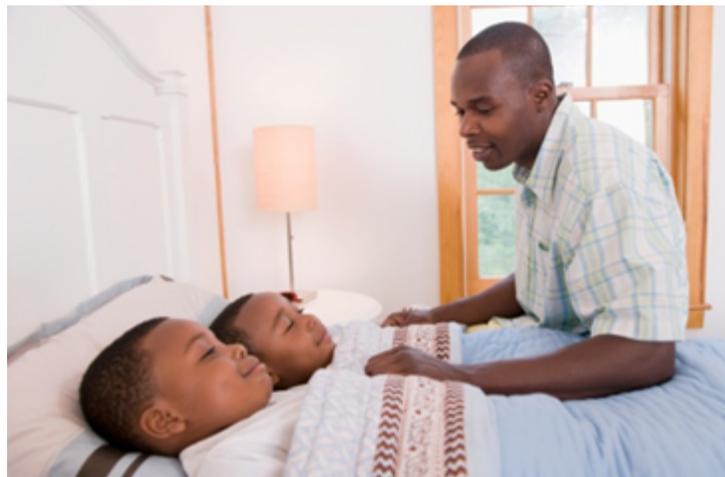
All of the children in the group are looking at books. However, one child is not interested in books. His attention span is very short and he prefers activities that involve movement. After a couple of minutes, he attempts to run out of the door toward the playground. It is possible that the boy is running away because he is bored with the current activity.

As you can see from these examples, challenging behaviours often relate to the child's disability—as with the youth with ASD dumping water because she finds the sensory experience enjoyable—and/or skill deficits—the child throwing beads because she is unable to communicate her displeasure in a more appropriate manner. Therefore, one of the most effective ways to reduce challenging behaviours is to expand the child or youth's current skills.

Challenging behaviours may also be a part of typical development as children and youth experiment with their environment. An example is a child wondering, “What will happen if I drop my lunch on the floor...or throw my toy?” It is only when these behaviours persist over time, become disruptive, cause harm, or interfere with learning that intervention is necessary.

Developing the knowledge and ability to teach will allow you to improve the life of your child in the following ways:

- Increasing their personal independence and skills
- Reducing/eliminating challenging behaviours



Deciding What to Work On

The key to successfully changing someone's behaviour is to teach them appropriate and adaptive ways to meet their needs.

It is important to think about the following when identifying what new skills need to be taught to your child:

Alternative behaviours that would serve the same purpose. Think of it this way: "If the child could [identify a specific skill], he would no longer need to [challenging behaviour you hope to reduce or eliminate]."

Examples:

- If Samuel could gain attention by tapping his mother on the shoulder he would no longer need to scream to get her attention.
- If Natalie could tell us when she is hungry, she would not longer need to tantrum when she wants to eat.
- If Michael could request a break when we are doing laundry, he would no longer need to throw the laundry basket to tell me he is getting bored or frustrated.

Incompatible behaviours that would prevent the child from engaging in the challenging behaviour. Think of it this way "If the child learned to [identify a specific skill], it would be impossible, or at least difficult, for him to [challenging behaviour you hope to reduce or eliminate]."

Examples:

- If Shelley learned to hold my hand during walks, it would be difficult for her to run away.
- If Nathaniel learned to sit on his square during circle time, it would be difficult for him to touch his peers during story time.

Reducing frustration. Think about the tasks or situations that tend to result in frustration and, therefore, lead to challenging behaviour.

Examples:

- Jamie often screams and drops to the floor when he is unable to open the zipper on his lunch bag. Therefore, teaching him how to open his lunch bag may help to reduce his tantrums. Alternatively, it may be helpful to provide Jamie with a lunch bag with a Velcro closure rather than a zipper.

- Michelle often hits her Aide during craft activities as she has difficulty with fine motor tasks, such as colouring and cutting. Improving her fine motor skills may help to reduce this behaviour.

Increasing tolerance and coping skills. Sometimes children and youth display challenging behaviours to “escape” from situations that they find unpleasant. For instance, children with ASD often find certain sensory experiences aversive. One of the ways to reduce challenging behaviour is to increase the child’s tolerance and coping skills gradually. This is especially important if the situation or thing they find unpleasant is one that they are likely to encounter throughout their life.

Examples:

- Louise often places her hands over her ears and screams when she hears other people singing. Therefore, increasing her tolerance for singing might be an appropriate goal as she will likely encounter singing throughout her life.
- Mitchell often engages in self-injurious behaviours when he is in crowded areas. Therefore, increasing his ability to cope in large groups may be an appropriate goal.

Your Turn

William often attempts to hit his mother during play activities with his brother and sister. What are some of the skills you could teach him to reduce hitting?

There are other important factors to consider when selecting goals. These are covered in other sections of this program. Following is a review of points to consider about goals:

- Meaningful/functional for your child and family
 - Think about how life would be different if the goal was achieved. If you can’t think of significant positive changes, then the goal is likely inappropriate.
 - Think long-term—goals should be future-oriented and focus on skills that your child and family will need to be successful eventually.
- Culturally responsive
 - It is important to consider your family’s values and practices. For instance, it would be inappropriate to work on teaching your child to use a fork if the family typically uses chopsticks.
- Consistent with the child’s developmental level
 - It is not appropriate to work on reading with a child that is functioning at a two-year-

old level, just as it is probably inappropriate to work on social games such as peek-a-boo with a 16-year-old.

- Individualized

- Every child and family is unique. Therefore, individualizing programs to address your unique needs is essential. What works for one child or family may not be effective or appropriate with another.

- Building on strengths and interests

- Goals that take your child's existing skills and interests into account are likely to have a positive effect on self-esteem and motivation to learn.
- Building on your child's strengths may result in improvements in other areas. For instance, expanding your child's gross motor skills to the point she can participate in sports may result in increased acceptance by peers and increased opportunity for interaction.

- Future-oriented

- Keep in mind the skills that your child or youth will require to experience success when they are older. What is appropriate at one age may not be appropriate for an older child.

Applying Teaching Strategies

So you've come up with the skills you would like to teach...now what?

This is where you put the teaching strategies described earlier in "Teaching Adaptive Behaviour Unit", into action. Although you can use these strategies to teach just about anything, we will focus on the skills that children and youth with developmental disabilities often require help to learn.

Communication Skills

Possible Communication Goals

Children and youth often require help to learn the following:

- Gaining the attention of others
- Asking for desired items/activities or for help
- Rejecting unwanted items/activities

Communication Encompasses More than Words

There are many different ways to communicate with others. We often refer to these as modes of communication. For instance, there are many different ways a child could tell others that he wants a drink of juice:

Modes of Communication	Examples
Leading/Guiding	Child takes his mother's hand and places it on the juice container
Gestures	Child points or reaches towards the juice container
Object	Child lifts up his glass
Visual symbol—photograph, picture symbol, written word(s)	Child hands his mother a picture or photograph of the juice container
Sign language	Child produces the sign for juice
Verbal	Child uses words, phrases or sentences to ask for juice

Some modes are very concrete—leading/guiding—while others are quite abstract and require symbols such as a picture, words or sign language. A symbol is something that represents or signifies something else. For instance, a picture of a juice container is a symbol for the actual juice container.

Determining which modes are appropriate for a particular child or youth generally involves consultation with a Speech Language Pathologist and consideration of several factors about the child:

- **Interests**—some children demonstrate a natural interest in one mode over another
- **Motor skills**—sign language can be difficult for children with fine motor problems
- **Cognitive abilities**—children with significant cognitive delays are often more successful with modes that are more concrete
- **Previous experience with different modes**—what they have been exposed to in the past and how successful it has been
- **Home and school environments**—what communication systems are used

Food for Thought

Take a minute and think about how you would communicate with others if you were not able to use words. How would you tell others that you are hungry, frightened or not feeling well? What would you do if others did not understand your message? It is easy to see why many children and youth use behaviour to communicate.

Teaching Communication Skills: Requesting

Creating Teaching-Learning Opportunities

Take a step back and consider your child's interests and preferences. Try to think of items they are genuinely motivated to have, activities they appear to enjoy and situations where they are motivated to seek out help. You can create a "likes list" with these items.

In teaching-learning situations, your child must request to get their needs met, therefore providing an opportunity for teaching and practice. In order to create these opportunities, you may need to alter the environment to make sure that your child cannot meet his needs on his own:

- Putting toys out of reach
- Putting food items in containers that they are unable to open
- Failing to provide your child with something they need to complete an activity, such as giving them a worksheet but no pencil

Try not to anticipate your child's wants and needs. Rather, wait expectantly for him to do something to indicate what they want.

Prompting

In the early stages while your child is learning the skill of requesting something she wants, you will need to stay quite close to your child so you are ready to assist and support her. You can do this by providing her with prompts.

It is important to choose the correct type of communication for the skill you are teaching, because some prompts may be inappropriate in a given situation. For instance, you cannot physically prompt a verbal response. Similarly, you may decide not to use model prompts if your child is unable to imitate.

Example:

Teaching a child to request a favourite food item—a cookie in this example.

The following table shows all levels of prompting, but you will notice that not all prompts are appropriate for this example. As mentioned earlier, you would not typically include every single prompt, but only those that are appropriate to the child and the skill you are teaching.

Description of Teaching/Prompting	Mode of Communication			
	Leading/Guiding	Picture Symbols	Sign Language	Words
Physical Prompting	Parent physically assists child to guide/lead another person to the cookie	Parent physically assists child to hand a picture symbol for “cookie” to another person	Parent physically assists child to produce the sign for “cookie”	Not appropriate
Model	Generally not used	Parent demonstrates how to hand the picture symbol for “cookie” and then provides time for child to imitate	Parent demonstrates how to sign “cookie” and then provides time for child to imitate	Parent models the word “cookie” and then provides time for child to imitate
Gesture	Generally not used	Parent points to the cookie or a picture symbol for “cookie” and/or puts their hand out to receive the picture symbol	Parent points to the cookie or a picture symbol for “cookie”	Parent points to the cookie
Visual Support	Generally not used	Parent signs as a reminder to the child to request	The child is shown a picture or photograph of cookie	Parent shows child a picture of a cookie or signs “cookie” to cue them to produce the word
Verbal Prompt	Generally not used	Parent provides a verbal reminder, “What do you want? Use your pictures.”	Parent provides a verbal reminder, “What do you want?”	Parent provides a verbal reminder, “What do you want?”
Independent	Child guides another person’s hand toward the cookie	Child picks up picture symbol for “cookie” and hands it to someone	Child produces the sign for the item they wish to have	Child says “cookie” to another person

Considerations when Using Prompting

In many situations, it is helpful to have a second person to make the teaching more natural. For example, the second person could physically assist your child to sign to you.

As skills improve, prompting should be carefully faded. Verbal modeling is the most challenging type of prompt to fade when teaching communication skills. Giving your child the words she should use—in the above example, cookie—may not be teaching your child to communicate her request because she

may actually be repeating the word she hears you say. Communication is more than repeating what other people say; to ensure that your child is communicating—and not simply repeating the words—it is often helpful to use a visual prompt such as a picture or a sign rather than saying what you expect your child to say. It may also be beneficial to repeat the original question after using a verbal model.

Example:

Parent: “What do you want?”

Child: No response

Parent: “Cookie.” (Parent provides verbal model.)

Child: “Cookie.”

Parent: “What do you want?” (Repeats question to teach child how to respond without verbal model.)

Child: “Cookie.”

- Pairing the word—cookie, for example—with the picture, object, sign or gesture will generally increase understanding.
- To improve motivation, take your child’s interests and preferences into account; reinforcement occurs naturally when your child receives something special to him that he has requested.

Teaching Communication Skills: Rejecting

Create Teaching-Learning Opportunities

As rejecting is the opposite of requesting, your first job is to think of items and activities that are NOT motivating for your child. You learned about creating a “likes list” in topic 5. Now it is time to create a “dislikes list.” It is usually helpful to order the items and activities in terms of how much your child dislikes them, from “Dislikes a little,” to “Dislikes a lot.”

The first teaching-learning opportunities you create should focus on an item or activity that your child dislikes a little. Starting with something she really dislikes could lead to your child using negative behaviour to communicate. As her skills improve and she learns that she has the power to say no to things, introduce items and activities that are lower on her “dislikes” list.

Create opportunities for your child to reject by offering her an item from her dislikes list:

- Offer a food item that your child does not like at snack time.
- Offer your child a toy that she does not enjoy playing with.

Over time, children must learn that there are things in life that are non-negotiable, such as going to bed, wearing a coat during the winter, brushing teeth, and that ultimately adults make some decisions. When children start to generalize their rejecting skills, it is

often necessary to acknowledge their communication by informing them that you recognize that they don't want to engage in a specific activity, and explain why their participation is required.

Prompting

It is important to jump in with prompting before your child attempts to use their behaviour to reject. Remember, old habits can be hard to break especially when they have been effective for your child in the past.

Once again, the prompting sequence will vary depending on your child's learning style and the skill you are teaching.

Example:

Teaching a child to reject yogurt in an appropriate manner, rather than throwing it.

Description of Teaching/Prompting	Mode of Communication			
	Pushing/Giving	Picture Symbols	Sign Language	Words
Physical Prompting	Parent physically assists child to give back or push away the yogurt	Parent physically assists child to hand picture symbol for "finished" to another person	Parent physically assists child to produce the sign for "finished"	Not appropriate
Model	Parent models giving back or pushing away the yogurt	Parent demonstrates how to hand the "finished" picture symbol to another person	Parent demonstrates how to sign "finished" and then provides time for child to imitate	Parent models the word "finished" and then provides time for child to imitate

Description of Teaching/Prompting	Mode of Communication			
	Pushing/Giving	Picture Symbols	Sign Language	Words
Gesture	Parent puts their hand out to cue the child that it is okay to give it back	Parent points or gestures to the finished symbol and extends their hand to accept it	Generally not used	Generally not used
Visual Support	Generally not used	Parent signs as a reminder for the child to reject (e.g., signing “finished”)	The child is shown the picture symbol for “finished”	Parent shows child a picture symbol for “finished” or signs “finished” to cue her to produce the word
Verbal Prompt	Parent provides a verbal reminder “You can give back”	Parent provides a verbal reminder “What can you do?”	Parent provides a verbal reminder “What can you do?”	Parent provides a verbal reminder, “What do you want?”
Independent	Child gives back or pushes the yogurt away when it is presented	Child picks up picture symbol for “finished” and hands it to someone	Child produces the sign for “finished”	Child says “finished” to another person

The child is motivated to use appropriate behaviour when his efforts are rewarded in the following ways:

- Honouring or accepting his rejection
- Taking away the unwanted item
- Stopping the activity

Teaching Communication Skills: Gaining the Attention of Others

Creating Teaching-Learning Opportunities

It is important that your child learn to request before expecting them to gain the attention of the person they are trying to communicate with. That is, you should generally make yourself available to the child when

teaching requesting, rather than expecting your child or youth to do something to get your attention. Your child needs to know that it is “worth their time” to approach others before trying to teach them to use a word, sign,

picture symbol or gesture to gain the attention of others. In this case you would try to think of situations where the child “needs” you – needs you to help them, needs you to give them something, etc.

When you teach requesting and reject-

ing, you position yourself close to your child and make yourself readily available. When teaching your child to gain attention, you position yourself away from your child and expect them to do something appropriate to gain your attention.

Prompting

There are many different ways to gain someone’s attention; here are a few examples

- Tapping on shoulder or touching arm
- Approaching someone and handing them a picture symbol or signing to them
- Calling the person’s name

Example:

Teaching the child to gain attention to get help with their zipper.

Description of Teaching/Prompting	Mode of Communication		
	Touching to gain attention	Approaching person to gain attention	Using words to gain attention
Physical Prompting	Parent physically assists child to touch another person on the arm or shoulder	Parent physically guides child toward another person before making a request	Not appropriate
Model	Parent models touching another person on the arm or shoulder	Parent demonstrates how to approach another person before making a request	Parent models calling the other person’s name
Gesture	Generally not used	Parent points or gestures to the person that can help them	Parent points or gestures to the person who can help the child
Visual Support	Generally not used	Parent shows the child a picture symbol of the person that can help the child	Parent shows the child a picture symbol of the person who can help the child
Verbal Prompt	Generally not used	Parent provides a verbal reminder “What can you do?”	Parent provides a verbal reminder “What can you do?”
Independent	Child touches the person on the arm or shoulder	Child approaches another person and asks for help using the picture symbol or sign for zipper	Child call the name of the person in the room that can help the and asks for help with their zipper

Final Thoughts on Teaching Communication Skills

You should now be ready to start teaching communications skills using the techniques described so far. You can use the same basic prompting sequences to teach other communication skills—commenting, asking questions, and answering questions, for example.

Once children start to use words to communicate, it is tempting to push for phrases and sentences. Keep in mind that it is necessary to possess an extensive vocabulary of nouns, verbs and description words to be able to form a sentence. Also, it is not functional to teach a child to memorize and use words that they do not understand. It is more functional for a child to say “sandwich” and know what

they are saying than to expect them to say “I want sandwich please” when the only word they truly understand is sandwich. Although society values manners, if words such as “please” and “thank you” are introduced too early, they often become part of rote-learned script and are used incorrectly.

Focus on words and signs that are specific and refer to an actual object, item or activity that you can see—dog, table, cookie, jump—rather than nonspecific words that can be used to refer to multiple objects or actions—more, help, thing. Nonspecific words can actually hinder vocabulary development as they can be used in a multitude of situations.

Resources for Teaching Communications Skills

Here are some resources you might find helpful:

Freeman, S. & Dake, L. (1996). *Teach me language: A language manual for children with autism, Asperger’s syndrome and related developmental disorders*. Langley, BC: SKF Books.

Hodgdon, Linda A. (2000). *Visual Strategies for Improving Communication: Practical Supports for School and Home*. Troy, MI: QuirkRoberts Publishing.

Kumin, L. (2003). *Early communication skills for children with Down syndrome: A guide for parents and professionals*. Bethesda, MD: Woodbine House.

Pepper, J. & Weitzman, E. (2004). *It takes two to talk: A practical guide for parents of children with language delays*. Toronto, ON: Hanen Centre.

Quill, K. (1995). *Teaching children with autism: Strategies to enhance communication and socialization*. New York: Delmar.

Quill, K. (2000). *Do-watch-listen-say: Social and communication intervention for children with autism*. Baltimore, MD: Paul H. Brookes.

Schwartz, S. (2004). *The new language of toys: Teaching communication skills to Children with special needs, a guide for parents and teachers*. Bethesda, MD: Woodbine House.

Sigafoos, J., Arthur-Kelly, M. & Butterfield, N. (2006). *Enhancing everyday communication for children with disabilities*. Baltimore, MD: Paul H. Brookes.

Sussman, F. (1999). *More than words: Helping parents promote communication and social skills in children with autism spectrum disorder*. Toronto, ON: The Hanen Centre.

Social Skills

Identifying Goals

Children need a wide variety of social skills in order to establish and maintain relationships and experience success in social situations. Typical social interactions are guided by a set of customary social rules and norms.

Some social rules are quite concrete:

- Saying excuse me after burping
- Responding when others say hello

Others are quite abstract:

- Determining when it is appropriate to hug someone
- Knowing when the person you are talking to is getting bored

When establishing treatment goals, it is often helpful to observe your child or youth in a social setting — at the park, with siblings, at a play group, during a coffee break at their work placement. Try to identify skills that would make them more successful socially and increase peer acceptance.

Applying Teaching Strategies

Some common teaching strategies for teaching social skills follow:

Social Scripts

Social Scripts, also called Social Stories, are a special kind of visual support. They outline how a child should respond in a specific social situation and can be used to teach a wide variety of social skills. They tend to be particularly useful when trying to teach an abstract social skill, as they allow you to make the skill as concrete as possible. Social Stories are usually developed specific to the needs of each child with the support of a Speech-Language Pathologist.

Modeling

Modeling involves showing or demonstrating the skills that you would like a child to learn. Remember, typically developing children learn a great deal from each other, so using peer models can be a very effective teaching tool.

Jessica has difficulty introducing herself to others. Her mother suggested that her sister introduce herself first, which allowed Jessica to see how it should be done.

Role-playing

This involves creating and practicing a situation or sequence to develop the skills necessary for success.

Prior to going to school, William and his father role-played asking children to come to his birthday party. When he went to school, William knew the steps involved and asked three children to his party.

Prompting

Many children require prompting to cue them to display specific skills in social situations:

- Verbal directions—“Tell him your name”
- Visual supports—a picture symbol to remind a child not to crowd his friends
- Gestures—pointing out a child who might want to play with them, pointing to your eyes to remind a child to make eye contact with the person he is speaking to
- Partial physical—touching the child to cue them to turn towards the child they are playing with

Motivation

For many children, interacting may not be motivating enough for them to want to play or interact with others. In the early stages of teaching, it may be necessary to establish a reward system to motivate the child to practice certain skills. As children experience social success, playing and interacting with others generally becomes more fun and motivating for them.

One of Brett’s goals is to learn to take turns with others. However, he generally prefers to play by himself. His parents set up a reward system that involved rewarding Brett with five minutes of computer time each time he played a turn taking game with another child.

Social Skills Training Groups

A Speech Language Pathologist, Psychologist or Teacher often runs these groups. They are usually designed to teach a specific set of skills in a structured manner. Keep in mind that teaching social skills in a group setting allows for practice with peers.

Videotaping

Videotaping provides a child with a chance to view herself in action, identify her successes and pinpoint her challenges.

Dermott tends to crowd his friends to the point that they avoid playing with him. His parents videotaped him playing on the floor with three other children. When he watched the videotape, Dermott was able to see when he got too close, and the effect it had on his friends.

Food for Thought

Take a moment to think of all of the social skills you have used today. To be successful in our social world, several skills are required. Also, try to think of the social dilemmas children commonly encounter, such as having to share a toy, deciding who goes first, dealing with bullying and cheating. These lists will help you identify specific skills to teach your child.

Example: Maintaining Appropriate Social Space

Louise is a five-year-old girl with autism. She is interested in other children and often attempts to join their play. However, she frequently leans on others, sits too close, and touches them. Some of the children in the playgroup have started to avoid Louise because they don't like it when she crowds or touches them. Here are the strategies Louise's parents used to address the situation:

Concrete rules

Given that social space is a very abstract social rule, Louise's parents started out by making the rule more concrete. They decided to teach Louise to sit/stand at least one arm's length from people.

Social stories

A social story was developed to remind Louise to leave an arm's length of space when she is standing in line, sitting on the floor, playing at the house centre and sitting at the table.

Prompting

Initially Louise required physical prompting to cue her to move back and provide adequate social space. Over time, the prompting was faded to the point that her parents could use a gesture—pointing, in this case—to indicate when she was too close to someone else.

Opportunities for practice

Louise and her parents practiced standing and sitting. They provided Louise with feedback about whether she was sitting too close or just right.

Motivation

To increase Louise's motivation to try to follow her new social rule, a reinforcement system was introduced. Louise would be given five minutes to play on the computer if she remembered her rule for 30 minutes. Eventually reinforcement was faded by increasing the length of time Louise was expected to follow her rule—from 30 minutes to 60 minutes to a half day.

Generalization

Over time, Louise was expected to follow her rules regardless of who she was with—family, teacher, or Aide—or where she was—home, school, community.

Example: Turn-taking

Michael is interested in other children, but generally plays by himself during free time. When others attempt to join him, he continues to focus on the toy and often becomes distressed if others attempt to touch it.

Concrete rules

Michael's parents developed a visual support to help him understand the concept of turn taking. The card had an arrow on it which could be turned to point to a picture of Michael or a picture of his mom or dad.

Prompting

Initially Michael required physical prompting to allow his mom or dad to take a turn. Over time, the prompting was faded to the point that Michael passed the toy to his mom or dad when asked—verbal prompting—and eventually passed it independently.

Opportunities for practice

To increase the likelihood of success, his parents started by using toys that Michael was interested in, but were not highly preferred. In addition, his parents did not expect Michael to take turns with other children until he was able to do so fairly consistently with adults. Initially, turn taking activities were kept quite short and Michael was only expected to take three turns. The activities were increased in length over time.

Motivation

Given that Michael preferred to play on his own, his parents developed a reward system to motivate him to take turns. The system was outlined visually for Michael using picture symbols to represent turn taking first and then going to the park.

Generalization

Eventually Michael was expected to engage in a wide variety of turn taking activities, such as puzzles, games, and computer, with different partners—parent, Aide, sibling, peer—across all environments, including home, school, and community.

Example: Initiating Interaction/Asking Someone to Play

Omar is able to share, take turns and play simple games. Although his comprehension is quite good, he is not able to communicate verbally and often “barges” into activities without asking, or drags children by the hand when he wants to play with them.

Social stories

A social story was developed to assist Omar to understand how to ask others to play. The story directed him to approach another child and ask him to play by handing him a picture symbol. The social story also helped to prepare Omar for the real world where invitations are sometimes rejected. It warned him that some children may say no, and if they did, he needed to find someone else to ask.

Prompting

In the beginning, Omar required physical prompting to hand the picture symbol to other children. Eventually this was faded to verbal prompting; “Omar, give him the picture;” and finally, Omar was able to do it on his own.

Peer coaching

To ensure success, his parents encouraged Omar to approach children that were likely to say yes to his request. Also, his parents spent time talking to the other children in the area about being a good friend to Omar and praising them for doing so.

Motivation

His parents knew that Omar was very motivated by stickers, so, they developed a sticker reward system to motivate Omar to ask children to play. Each time he asked a child to play with him a sticker was placed into his sticker book.

Generalization

Over time, Omar was expected to initiate interactions with a wide variety of people—sibling, familiar peers, less familiar peers—across a variety of settings--home, school, boy scouts).

Resources for Teaching Social Skills

Here are some resources you might find helpful:

Alberta Education. (2008). Supporting positive behaviour in Alberta Schools: An intensive individualized approach. Edmonton, AB: Author.

Baker, J. (2001). The social skills picture book. Arlington, TX: Future Horizons.

Dowd, T. & Tierney, J. (2005). Teaching social skills to youth. Boys Town, NE: Boys Town Press.

Garcia Winner, M. (2000). Inside out: What makes a person with social cognitive deficits tick? San Jose, CA: Author.

Garcia Winner, M. (2002). Think about you thinking about me. San Jose, CA: Author.

Leber, N. (2002). Easy activities for building social skills. Jefferson City, MO: Scholastic.

Mannix, D. (1993). Social skills activities for special children. San Francisco: CA: Josey-Bass.

McFee, J. (2002). Navigating the social world: A social skill curriculum. Arlington, TX: Future Horizons.

McKinnon, K. & Krempa, J. (2002). Social skills solutions: A hands-on manual for teaching social skills to children with autism. New York: DRL Books.

Weiss, M. & Harris, S. (2001). Reaching out, joining in: Teaching social skills to young children with autism. Bethesda: MD: Woodbine House.

Quill, K. (1995). Teaching children with autism: Strategies to enhance communication and socialization. New York: Delmar.

Quill, K. (2000). Do-watch-listen-say: Social and communication intervention for children with autism. Baltimore, MD: Paul H. Brookes.

Siperstein, G. & Rickards, E. (2004). Promoting social success: A curriculum for children with special needs. Baltimore, MD: Paul H. Brookes

Self Care and Life Skills

Identifying goals

People require a wide variety of skills to function independently. It is important to consider your child/youth's age, developmental level, and home environment when selecting goals. A comprehensive list of potential goals would be very long; some goals are shown below:

•Dressing skills

- Closing fasteners
- Putting on clothing items
- Orienting clothing
- Selecting clothing that is appropriate for the weather/situation

•Toilet training skills

- Voiding and having bowel movements on the toilet
- Wiping self
- Pulling pants up/down

•Washing skills

- Hand washing
- Face washing
- Bathing
- Washing hair

•Tooth brushing**•Mealtime Skills**

- Drinking from a cup
- Using utensils—spoon, fork, knife

•Health-related skills

- Using tissues/caring for nose
- Applying sunscreen, lotion, lip balm
- Taking required medications
- Shaving
- Clipping fingernails and toenails
- Putting on deodorant
- Menstrual hygiene

•Safety skills

- Responding to safety instructions such as stop
- Street safety
- Vehicle safety—leaving seat belt on, for example
- Stranger awareness
- Relating personal information when lost

•Household chores

- Putting away possessions
- Making bed
- Wiping surfaces
- Laundry
- Setting table
- Washing/drying dishes
- Snack/meal preparation
- Sweeping/vacuuming/washing floors

Applying Teaching Strategies

Task Analysis

Many self-care routines and chores require multiple steps. It is often helpful to break tasks down into concrete, simple steps when teaching them to individuals with developmental disabilities.

Helpful hint: There are many different ways to brush your teeth. Some people start with their front teeth, some start with the back. Children and youth tend to be more successful when the teaching is consistent and everyone approaches the task in the same way. Therefore, it is important to devise a task analysis that everyone agrees on and can live with.

Here are some sample task analyses to give you some ideas:

Using the Bathroom

- Requests/goes to bathroom
- Locates bathroom
- Turns doorknob
- Opens door
- Enters bathroom
- Closes door
- Pulls pants down
- Sits on toilet
- Voids in toilet
- Wipes self
- Gets off toilet
- Pulls pants up
- Flushes toilet
- Walks to sink
- Turns on water
- Washes hands
- Turns off water
- Dries hands
- Opens door
- Returns to original location

From Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Alberta Education. p. 178

Prompting

Keep in mind that the ultimate, long-term goal is for your child/youth to learn to complete the task as independently as possible. For some children this means completing the task without any help or coaching and without direct supervision. Therefore, it is critical to consciously fade prompting over time.

Motivation

Depending on your child or youth, it may be necessary to introduce some type of reward system to motivate her to cooperate and participate in self-care routines and daily living tasks. For instance, it is often helpful to use a different type or level of reinforcement when your child completes a step more independently than she has in the past. This should motivate her to demonstrate increased independence over time.

Your Turn

Develop a task analysis for making coffee. Remember to include every step that needs to be completed. To determine how well you did, use the task analysis to give someone else instructions. If your task analysis is accurate, the result should be a hot cup of coffee. Avoid trying this first thing in the morning—just in case!

Example: Hand washing

Rahim is a six-year-old boy with significant cognitive delay and limited communication skills; he uses picture symbols to communicate requests. He generally requires physical assistance to complete self-care tasks. Here are the strategies that Rahim's mother used to teach him how to wash his hands.

Task Analysis

Rahim's mother started out by developing a step-by-step task analysis. She discussed the situation with Rahim's Aide, nanny, and teacher to make sure that everyone agreed about the steps and order. The task analysis consisted of the following steps:

1. Turn on cold water
2. Turn on hot water
3. Adjust water temperature
4. Wet hands under faucet
5. Push down on liquid soap dispenser
6. Rub hands together
7. Wet hands under faucet to rinse
8. Turn off hot water
9. Turn off cold water
10. Pick up towel
11. Dry hands with towel
12. Return towel to counter

Forward Chaining

Because Rahim tends to be most success when new skills are taught in a methodical fashion, it was decided to teach him hand washing using forward chaining. This involved teaching Rahim the first step, and then adding on the second step once he mastered the first step.

Prompting Sequence

His mother also talked to all of Rahim's caregivers to come up with a prompting sequence. It was decided that the following sequence would be used:

- Independent— no support/coaching provided
- Verbal prompting—verbal instruction provided
- Visual support prompt— picture symbol shown to Rahim
- Gestural prompt— pointing/gesturing to cue Rahim to complete step
- Model prompt—step modeled for Rahim to imitate
- Partial Physical— Rahim physically guided to complete step
- Full Physical— Aide used hand over hand prompting to assist Rahim to complete step

Visual Supports

Due to Rahim's cognitive challenges, his mother thought it would be beneficial to have the task analysis outlined in pictures. His mother used the pictures when prompting him to complete the required steps.

Motivation

To encourage Rahim to cooperate during hand washing, praise was provided intermittently throughout the task. Each time he completed a step in a more independent fashion than he had done so in the past, his mother also gave him a pat on the back (differential reinforcement). At the conclusion of the task, Rahim was given an opportunity to play with water toys in the sink.

Example: Doing up Buttons

Grace has limited fine motor skills and a relatively short attention span, so she usually requires physical prompting to close fasteners—zippers, buttons, snaps, etc. She is required to wear a uniform at school that involves a shirt with buttons. Because she will be attending this school for several years, her team decided that doing up buttons would be an appropriate treatment goal.

Teaching Approach

Because of Grace's attention problems, it was decided that managing buttons would be taught using a discrete trial approach. Using this teaching method allowed the task to be taught in an environment with minimal distractions—at a table in Grace's bedroom—and ensured that there would be multiple teaching opportunities per day. It was decided that Grace would be encouraged to manipulate at least 15 buttons per day.

Consultation

To determine the best way to approach the task, an Occupational Therapist was consulted. She suggested teaching Grace the following sequence:

1. Do up large buttons on fastener board
2. Do up large buttons on shirt that she is not wearing
3. Do up large buttons on a shirt that she is wearing
4. Do up small buttons on a shirt she is wearing

Prompting sequence

Prior to the start of teaching, the team decided which prompts they were going to use and how they would be ordered. They used the following:

- Independent—no support/coaching provided
- Verbal prompting—verbal instruction provided
- Model prompt—showing Grace how to do up button
- Partial Physical—physically guiding Grace to do up button
- Full Physical—adult uses hand over hand prompting to assist Grace to do up button

Task Variation

Grace's limited fine motor skills makes tasks such as doing up buttons quite frustrating. To increase cooperation and to make sure that she frequently experienced success, the team decided to use task variation; the button trials were interspersed with other activities that Grace enjoyed and was good at—using cause-effect toys, social games.

Motivation

The team developed a card with 15 circles on it and a picture of a CD player. Each time Grace worked on doing up buttons, a check mark was placed in one of the circles. When all of the circles were full, Grace was given an opportunity to listen to music.

Example: Making a Snack

Arnie is a 13-year-old boy with an Autism Spectrum Disorder. He is required to bring his lunch to school each day. Arnie's team decided that making a sandwich would be a useful skill for him to develop.

Task analysis

The team sat down and came up with the following:

1. Get bread from counter
2. Get butter, mayonnaise and meat from fridge
3. Get knife from drawer
4. Place two slices of bread on counter
5. Spread butter onto bread
6. Spread mayonnaise onto bread
7. Place piece of meat on one slice of bread
8. Put one slice of bread on top of other
9. Put sandwich into plastic container
10. Put container into lunch bag

As was the case with Rahim, Arnie's team also developed a prompting sequence and taught the task using forward chaining.

Teaching Toilet Training

Teaching your child toilet training is often a stressful task for parents, which can be made even more challenging when your child has a developmental disability. Here are some strategies and suggestions.

Gather Information

It is often helpful to determine if your child/youth is aware when they have an accident, when accidents typically occur and how your child does when asked to sit on the toilet—for example, how long do they sit for, the behaviour displayed when asked to go to the bathroom. The information you collect will help you to develop your treatment plan.

Shaping and Reinforcement

As your child experiences success, slowly eliminate the adult-directed trips to the washroom. This will encourage your child to initiate on her own.

Increasing Awareness of Being Wet

Modern disposable diapers are very absorbent, and children who wear them often do not experience wetness when they have an accident. To increase their awareness and, hopefully their motivation to use the toilet, it is often helpful to have the child/youth wear underwear or training pants, rather than diapers or pull-ups, to increase their awareness of being wet.

Motivation

Many children/youth are not intrinsically motivated to void or have bowel movements in the toilet. Therefore, it is often beneficial to introduce an incentive or reward system. This might involve the following:

- Providing a reward to your child when they actually void or have a bowel movement in the toilet
- Providing a reward at regular intervals if your child/youth's pants remain dry

Visual Supports

To make the reward system as concrete as possible it is often helpful to outline the plan using pictures or picture symbols. Alternatively, some families find it helpful to have the reward in a container in the bathroom to show their child; for example, first pee in toilet, then get a marshmallow.

Time Training

Once your child is able to sit on the toilet, it is helpful to establish a routine or schedule. Depending on your child/youth and the frequency of accidents, you may want to take them to the bathroom as often as once every half-hour. For other children it may be sufficient to take them at specified times, such as after lunch, before supper, before bed.

Waiting Game

The most difficult part of toilet training is waiting for the first success. Be patient and avoid putting too much pressure on your child. It is critical that toilet training not become a negative experience.

Self-Initiation

As your child experiences success, slowly eliminate the adult-directed trips to the wash-room. This will encourage your child to initiate on her own.

Communicating Need

Give some thought to how your child/youth typically communicates with others—words, signs, picture symbols, leading guiding. It is important to establish some way for your child/youth to let others know when she needs to use the bathroom.

Resources for Teaching Self-Care and Life Skills

Here are some resources you might find helpful:

Alberta Education. (1995). Essential and support skills for students with developmental disabilities. Book 2 of the programming for students with special needs series. Edmonton, AB: Alberta Education.

From Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Alberta Education.

Baker, B. (1989). Steps to independence: A skills training guide for parents and teachers of children with special needs. Baltimore, MD: Paul H. Brookes.

Baker, B. & Brightman, A. (2003). Steps to independence: Teaching everyday skills to children with special needs. Baltimore: MD: Paul H. Brookes.

Coucovanis, J. (2008). The potty journey: Guide to toilet training children with special needs. Shawnee Mission, KA: Autism Asperger Publishing Company.

Crissey, P. (2005). Picture directions: Building independence step by step. Verona: WI: IEP Resources.

Ersnsperger, L. & Stegen-Hanson, R. (2004). Just take a bite: Easy effective answers to food aversions and eating challenges. Arlington, TX: Future Horizons.

Mannix, D. (1992). Life skills activities for special children. San Jose, CA: Jossey-Bass.

McClannahan, L. & Krantz, P. (1999). Activity schedules for children with autism: Teaching independent behaviour. Bethesda: MD: Woodbine house.

Wheeler, M. (2007). Toilet training for individuals with autism or other developmental disabilities. Arlington, TX: Future Horizons.

Play Skills

Play is critical to development. It is through play that children expand their cognitive abilities and motor skills, learn to interact and communicate with others, and gain a deeper understanding of the world around them. Children and youth with disabilities often require assistance and teaching to learn to engage in developmentally appropriate forms of play.

Functional play involves using materials in a conventional manner, or as they were intended to be used. Here are some examples:

- Placing pieces into a puzzle
- Activating a cause-effect toy—pushing the button on a musical toy, for example
- Stacking blocks
- Stringing beads
- Placing pegs onto a peg board

Pretend play requires children to use their imagination and go beyond the current situation and materials. Initially, children learn to animate characters and use lifelike props or miniatures to reenact familiar sequences, such as putting the doll to bed. Over time, they learn to transform objects—pretending a block is a car—, take on roles and reenact sequences that they have not personally experienced, like putting out a fire, for example.

As children develop, their play tends to become more cognitively complex, progressing from object exploration to functional play—using objects in a functional or conventional manner—and from simple games to play that involves pretending.

There is also a social dimension to play. As they develop, children progress from solitary play to parallel play—playing independently beside another child—and, finally, to interactive forms of play. Interactive play involves two or more children engaging in reciprocal activity. That is, the other children involved in the activity influence each child's actions.

Food for Thought

Think about the children in your life: How much time do they spend engaged in play? Compare preschoolers to school aged children and teens. Do they spend comparable amounts of time engaged in play?

Now, think about children and youth who have limited play skills. How do they fill their day? Challenging behaviours are often the direct result of a skill deficit. For instance, a child that engages in destructive behaviours—ripping books, taking toys apart—may be doing so because he does not have the skills to occupy his time in a better, more adaptive manner. Remember, we all like to keep busy.

Common Goals Related to Play

Children and youth may require help to learn the following:

- Engage in functional play—using toys in an appropriate or conventional manner
- Engage in representational play—play involving lifelike props
- Engage in pretend or symbolic play—play that involves imagination
- Take turns with others during play
- Incorporate the suggestions/ideas of others during play
- Follow the rules associated with games
- Display good sportsmanship

Applying Teaching Strategies

Task Analysis

Asking a peer to play:

- Identify peer who is not currently playing with anyone
- Identify activity to play
- Approach peer
- Gain peer's attention by saying name or tapping him on the shoulder
- Establish eye contact with peer
- Ask peer if he would like to play
- Wait for peer to respond
- Commence activity if peer agrees to play, or approach another peer

From Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Alberta Education. p. 181

Motivation

For many children with developmental disabilities, play itself is not motivating or reinforcing. Therefore, it is often necessary to incorporate some type of reward system to motivate them to participate and expand their current play skills. Children with developmental disabilities often show increased interest in, and motivation to, play over time as they become familiar with the activities presented, and their skills increase.

During unstructured periods of the day, Shawn generally spends his time twirling string in front of his eyes or staring out the window at the trees. When toys are presented, he generally pushes them away or attempts to leave the area. To increase his motivation to engage in functional play, Shawn is provided with a string to twirl after he completes a simple puzzle.

Prompting

As you have learned, children with developmental disabilities often require assistance to learn new skills. This assistance can take many forms—verbal instructions, modeling, gestures, physical assistance—and should be carefully faded to encourage independence.

Although she displayed obvious interest in a cause-effect toy that produced music, Sabrina was not able to push the button to activate the sound. Initially, her mother provided her with physical prompting to push the button. As Sabrina experienced success, the physical prompting was faded and her mother cued her to push the button by modeling the required action. After a couple of days, prompting was faded to the point that all her mother had to do was verbally remind Sabrina to push the button. Finally, after she experienced repeated success, Sabrina began to push the button independently.

Peer Modeling

Keep in mind that children learn a great deal from watching and interacting with each other. Therefore, it is often beneficial to use peers to model specific skills. Here are some different ways to use peer models for expanding play skills:

- Modeling different ways to use toys—for example, demonstrating how to use a cookie cutter with play dough
- Building a structure using construction materials for the other child to replicate
- Demonstrating how to take on a specific role
- Modeling how to win and lose in a respectful manner—being a good sport
- Demonstrating how to keep their hands down when the other person is taking a turn
- Modeling the language to use during play

Visual Supports

Visual supports can be used a variety of ways to teach play skills. The following are examples:

Outline the steps or rules associated with a specific game

One of Liam's goals was to learn to play Chutes and Ladders. His parents developed a card that visually outlined the basic steps: roll dice, move marker, if you land on a ladder go up, if you land on a chute go down, pass the dice to the next person.

Indicate whose turn it is

Greg often grabbed at materials and interrupted the turns of others. His parents developed a visual support that had their own pictures and a picture of Liam. There was also an arrow that could be moved to point at each face. The arrow was used to indicate turns. Once Greg was familiar with the visual, his parents substituted their faces for the faces of two peers and used it to encourage Greg to engage in turn taking activities with other children.

Provide the child with ideas

Although Shelby appeared to be interested in playing with the farm set, her play consisted of repetitively putting the animals into the barn and then taking them out. Her parents developed a card that visually outlined different things she could do with the materials:

- Placing the horse by the water bucket
- Putting the pig to bed
- Walking the farmer up the stairs
- Putting the cow in the back of the truck

Provide a script of different things to say during the activity

As Shelby's play skills improved, her parents introduced a visual support to remind her of different things she could say to other children when she was playing at the farm centre.

Example: Occupying Free Time

Shamir is a 13-year-old with a developmental disability. Although he is able play with a number of different toys when he is specifically encouraged to do so, he tends to be quite destructive—peeling the paint off the walls, pulling threads out of the couch—when he is left on his own. Shamir's mother mentioned that it is very difficult for her to make supper, as she cannot let Shamir out of her sight. Here are the strategies Shamir's team used to address this situation:

Surveying play skills

First, the team made a list of all of the activities that Shamir could complete without assistance. The list included stringing beads, placing pegs into a Lite Brite, completing simple puzzles (25 pieces or less), completing simple mazes and dot to dot worksheets, and sorting playing cards according to suit.

Motivation

As Shamir did not appear to be intrinsically or naturally motivated to engage in independent play/activity, a reward system was introduced. The team decided that Shamir would be provided with an opportunity to swing in the backyard—something that was very motivating for him—each time he engaged in independent play.

Visual Support

The team also introduced a visual schedule to make expectations clear. The schedule initially consisted of two squares. A picture of an activity that Shamir could complete on his own was placed in the first square, and a picture of the swing in the second square.

Gradually increasing expectations

Shamir and his mother worked through the schedule several times. Once Shamir learned that he could go outside and swing when he was done, he displayed increased motivation to complete the presented activities. Over time, the team was able to achieve the following:

- increase the number of squares on the schedule so that Shamir was required to complete three activities before going outside to swing
- fade his mother's presence to the point that she was not in the room when Shamir completed the presented activities

Generalization

Once Shamir had the basic idea, other members of the team were asked to present the schedule to Shamir. An effort was also made to present the activities in different areas of the house—kitchen table, Shamir's bedroom, family room.

Example: Animating Figurines/Dolls

Maria is a 6-year-old girl with Asperger's Syndrome. She is able to play independently with a wide variety of functional play materials such as puzzles, matching activities and blocks. However, she displays little interest in play materials that involve figurines or dolls. This is problematic, as most of the girls in her class tend to gravitate towards the house centre, thus limiting her opportunity for peer interaction. Here is how Maria's team approached the situation:

Motivation system

Given that house centre and doll play were not motivating to Maria, her Aide identified some things that were. After consulting with her family and teacher, it was decided that Maria would be given a sticker each time she played with a doll.

Visual support

A card was developed that outlined six different play actions that involved dolls—feeding doll, putting doll to bed, burping doll, etc.

Prompting

During the initial stages of teaching, the Aide used prompting to encourage Maria to do different things with the doll. The following prompt hierarchy was used:

- Independent—no support/coaching provided
- Verbal prompt—telling Maria what to do—burp baby, for example
- Visual Support prompt—referring to the play card
- Model prompt—demonstrating the play action for Maria
- Partial physical prompt—physically guiding Maria to perform a play action

Peer models

Once Maria was familiar with most of the play actions, peers were incorporated into the doll play sessions. It was noted that once other children were involved, Maria was more focused on the play and her peers than she was on the stickers.

Helpful Hints

Start with an adult play partner

To increase the likelihood of success it is often helpful to introduce new play skills using an adult play partner. Adults offer several advantages:

- Take short turns
- Follow the rules
- Model socially appropriate behaviour and child friendly language
- Keep their hands to themselves when it is not their turn
- Allow for processing time (child longer turn)
- Remain in the area until the activity is complete
- Focus their attention on the activity
- Win/lose graciously
- End the activity when their partner loses interest
- Simplify the rules, as necessary

Creativity

Remember, children can only be as creative and flexible as the adults around them. It is often helpful to sit back and observe children at play to get ideas for themes/actions to introduce and model.

Flexibility

Avoid inadvertently reinforcing rigid patterns of behaviour and inflexibility; expose your child/youth to different ways of using toys, different rules, and different scripts/themes.

Pretend Play

When working on pretend play it is often helpful to follow the sequence outlined below:

- Actions, roles and events that your child has personally experienced—going to bed, taking a bath, having their hair cut
- Actions, roles and events that they have directly observed others performing, but not personally experienced—driving a car, making dinner
- Actions, roles and events that are beyond their experience—fighting crime, casting a spell

Using Props

During the initial stages of teaching pretend play, your child/youth may benefit from the use of props. As their skills increase, challenge them to use their imagination and fade the props (e.g., encouraging your child to brush his hair using a block as a brush and progressing to the point that your child brushes his hair with an imaginary brush).

Keep it fun!**Resources for Teaching Play Skills**

Here are some resources you might find helpful:

Jones, M. (1989). *Understanding your child through play*. Toronto: ON: Stoddart.

Schwartz, S. (2004). *The new language of toys: Teaching communication skills to Children with special needs, a guide for parents and teachers*. Bethesda, MD:

Smith, M. (2001). *Teaching play skills to children with Autism Spectrum Disorder: A practical guide*. New York: DRL Books.

Wolfberg, P. (1999). *Play and imagination in children with autism*. New York: Teachers College Press

Cooperation/Coping Skills

In this section, we will focus specifically on increasing cooperation and coping skills, two skills that are critical for learning and social acceptance.

Common Goals Related to Cooperation and Coping

Children and youth often require assistance in these areas:

- Follow the agenda of others/cooperate with adult directed task/activities
- Modulate level of arousal
- Seek out desired sensory feedback in an appropriate manner
- Increase tolerance for certain events/stimuli in their environment

Applying Teaching Strategies

By now you have probably noticed a theme; certain teaching strategies/methods tend to be effective regardless of the type of skill being taught.

Motivation

It is often necessary to establish an incentive system to encourage children and youth with developmental disabilities to cooperate, refrain from challenging behaviours and/or display appropriate coping skills. Typically developing children often display appropriate behaviour just because—just because they want to be accepted, they want the approval of those around them and they want to conform to societal norms. Children and youth with developmental disabilities often require, at least in the early stages of teaching, a meaningful reward for doing so.

Visual Supports

You have learned that Visual supports can be used in a variety of ways. If you are attempting to increase cooperation and teach coping skills, it is often helpful to use visual supports for the following:

Make expectations clear

This can be achieved by developing a visual depiction of rules using words and/or pictures, and generally involves specifying desirable behaviours—hands down, mouth quiet, for example. However, in some situations, it may be necessary to depict the behaviours you are trying to reduce or eliminate. Until your child or youth demonstrates a firm understanding of the meaning of no—as in, “No hitting,”—focusing on undesirable behaviours should be avoided; it could inadvertently increase a behaviour you want to reduce or eliminate. Remember, just because a child uses the word no does not mean they truly understand the word.

Make contingencies clear

Even though you have taken the time to identify very motivating rewards, your child's behaviour is unlikely to change if he does not understand the connection between their behaviour and gaining the reward. For instance, if you want to increase cooperation, you may use a visual to show your child that when he completes his laundry he can have a break in his room.

Outline how to behave in a specific circumstance

It is often helpful to use a social story or social script to remind your child to display appropriate coping and/or to refrain from challenging behaviours.

- Michael often cries and throws the materials when he loses a game. His team developed a social story to remind of the following:
 - Sometimes I win, sometimes I lose
 - Everyone loses sometimes
 - When I lose it is okay to say “maybe I will win next time”
 - When I lose it is not okay to get upset and throw things
- Vikram often gets upset when his routine is disrupted or things happen that are unexpected (e.g., having house guests, the DVD not working properly). He has a visual to remind him what he should do when he is upset: When I am upset, I can take deep breaths, squeeze my hands, go to my room, or count to ten.

Modeling

It is important to model the skills that we expect our children and youth to display. Children and youth with developmental disabilities tend to mirror the behaviours, reactions and language modeled for them. To emphasize specific points, it is often helpful to talk out loud; for instance, “I just lost the game, but that's okay, maybe I will win next time.” As noted earlier, peer models can be very effective when attempting to teach new behaviours and skills. In some cases, it may be beneficial to coach peers ahead of time to ensure they display the skills/behaviours we would like them to model.

Prompting

Depending on the skill being taught, it may be necessary to provide assistance/prompting to ensure your child is successful. For instance, it may be necessary to prompt your child to pick up their social script and refer to it at the conclusion of a game—when they lose, for instance.

Desensitization

This strategy involves gradually exposing your child/youth to something they find unpleasant or dislike doing. This technique tends to be most effective when the individual has been taught to use effective calming strategies—outlined below—and should only be used when the avoidance is problematic. Many people are afraid of bees and live happy productive lives. When the avoidance results in potentially unsafe behaviour—such as running into the road to avoid a bee—, interferes with social acceptance or learning, and/or impedes day to day

functioning—refusing to go outside because there might be a bee—, intervention may be warranted. Another key to success is that the exposure is very gradual. For a child who finds the sound of babies crying unpleasant, the exposure might consist of the following:

- Listening to a baby crying on tape with the volume turned to the lowest setting and gradually increasing the volume
- Encouraging the child stand outside of a room where a baby is crying
- Encouraging the child to wear earplugs and stand in the same room as a crying baby
- Encouraging the child to stand in the same room as a crying baby without the earplugs

Example: Increasing Cooperation

Gabe is a six-year-old with Fetal Alcohol Spectrum Disorder (FASD). Although he has the skill and comprehension to follow simple instructions, such as, “Come here,” “Put away,” “Get your shoes,” he often screams and drops to the ground when instructions are issued by adults. Interestingly, he generally has no difficulty when other children ask him to do things.

Motivation

Gabe’s team met in order to identify potential rewards. It was noted that he really enjoys watching cartoons. It was decided that the family would make an effort to limit Gabe’s access to cartoons to ensure that they remain motivating.

Visual support

A visual support was developed using five blank squares followed by a picture of a cartoon character. It also specified the reward system; “When I listen and follow instructions, I earn happy faces. When I have five happy faces, I get to watch cartoons.”

Opportunities for practice

To increase the likelihood of success, Gabe’s peers were encouraged to issue simple instructions for him to follow when the reinforcement system was introduced. When Gabe earned five happy faces, he was allowed to watch one cartoon. Once it was clear he understood that following instructions lead to watching cartoons, adult instructions were gradually introduced.

Generalization

To ensure that Gabe’s skills generalized across all caregivers and environments, all of the adults in Gabe’s life committed to using the reward system. This included his parents, teacher, grandparents, babysitter and cub scout leader.

Example: Seeking Out Sensory Feedback in an Appropriate Manner

Melanie is a ten-year-old girl with complex needs. She enjoys running her fingers through hair and often seeks out this type of sensory stimulation by touching and grabbing at others, particularly her sisters. Melanie's behaviour is very disruptive to the family and her sisters often avoid her.

Identify alternate ways to gain the same type of sensory stimulation

One of the first things her parents did was to try to identify other activities that would provide Melanie with the same type of sensory stimulation. The list included the following: running her fingers through her own hair; the hair on a hairdresser's mannequin; the fibers on a synthetic rug; and/or the "fur" on a fuzzy stuffed animal, or doll.

Motivation

As Melanie was very motivated to run her fingers through other people's hair, it was necessary to develop a reward system to motivate her to engage in the alternate sensory activities outlined above. Melanie's sisters mentioned that she really liked putting on flavored lip balm. It was decided that each time Melanie engaged in an alternate sensory activity, she would be given a chance to put on lip balm. Melanie's siblings also agreed to praise her for her efforts.

Visual support

To make sure that expectations were clear, a social script was developed. The script reminded Melanie that it was okay to touch her own hair, her doll's hair, her stuffed animals and the wig hair, but it was not okay to touch other people's hair. It also reminded her that when she sought out sensory stimulation in an appropriate manner, she would get to put on lip balm.

Example: Modulating Arousal

Many individuals with developmental disabilities have difficulty expressing their emotions appropriately, modulating their level of arousal, and calming down when they are upset. Petra is no exception. When she is asked to complete activities that she does not enjoy and/or when she is told no, she often screams, attempts to run out of the room and/or throws materials.

Identify calming strategies

Petra's team met to discuss potential calming strategies. Everyone agreed that Petra had the skills necessary to take deep breaths, squeeze a stress ball, and count to ten.

Visual support

A visual support was developed to remind Petra of the different calming strategies she could use when she was upset.

Opportunities for practice

Petra's parents demonstrated each of the calming strategies and encouraged her to do the same. Initially, these practice periods were conducted when Petra was calm and in a good mood. When all of the techniques were mastered, the visual support was presented to Petra when she was actually getting upset.

Motivation

Petra's parents noted that she tends to find the attention and praise of peers to be very motivating. Therefore, they asked peers to praise Petra for using her calming strategies and for remaining calm. Alternatively, peers were asked to refrain from talking to Petra when she was visibly upset.

Example: Increasing Tolerance

Brett tends to gag, cry, and escape from the area when he encounters “gooey” substances such as finger paint, yogurt, pudding or glue. He will be attending grade one next year so his parents thought it was important to increase his tolerance for “gooey” substances, as he will likely be exposed to them at school.

Motivation

Brett's parents noted that he really enjoys listening to music using earphones. To ensure that the activity remained motivating, Brett's access to earphones was limited to situations where he was exposed to gooey substances.

Identify calming strategies

Brett had previously been taught to take deep breaths when he was upset. It was decided that he would be encouraged to do so when gooey substances were presented.

Visual support

To ensure that Brett understood what was going on, a visual support was developed. The visual support reminded him to take deep breaths when he saw gooey substances. It also indicated that he would be given time to listen to music after “gooey time.”

Desensitization

Since Brett found gooey substances to be very unpleasant, expectations were increased very gradually to avoid overwhelming him. At first, he was expected to tolerate a gooey substance that was placed at the end of the table. As he experienced success, the substance was placed closer and closer to him. Following this, he was expected to place a paintbrush or fork into the substance. Finally, he was expected to touch the substance with his finger. After each exposure, Brett was praised for his efforts and given a few minutes to listen to music with his earphones.

Resources for Teaching Cooperation and Coping Skills

Here are some resources you might find helpful:

Baker, J. (2008). *No more meltdowns: Positive strategies for dealing with and preventing out-of-control behaviour*. Arlington, TX: Future Horizon.

Barkley, R. & Benton, C. (1998). *Your defiant child: 8 steps to better behaviour*. New York, NY: The Guilford Press.

Durand, M. (1990). *Severe behaviour problems: A functional communication training approach*. New York, NY: The Guilford Press.

Essa, Eva. (2007). *What to do when: Practical guidance strategies for challenging behaviours in the preschool*. New York: Delmar.

Hodgdon, L.A. (1999). *Solving behaviour problems in autism: Improving communication with visual strategies*. Troy, MI: Quirk Roberts Publishing.

Martin, G. & Pear, J. (2006). *Behaviour modification: What is it and how to do it* (8th ed.). Upper Saddle River, NJ: Prentice Hall.

Puberty/Sexuality

If you have older children or teens in your family, you are likely to encounter issues related to puberty and sexuality. Puberty can be a challenging time for typically developing children, and for those with developmental

disabilities, an even greater challenge. The situation is further complicated by the fact that sexuality involves many sensitive issues and some people find the topic uncomfortable to discuss.

Common Goals Related to Puberty and Sexuality

Children and youth often require assistance to learn about the following:

- Privacy/modesty—concepts of public and private
- Anatomy—appropriate terminology
- Establishing appropriate boundaries around masturbation
- Personal hygiene

Applying Teaching Strategies

Teaching sexuality-related concepts is really no different than teaching other social skills. Please refer to the strategies mentioned earlier. Here are some helpful hints:

Start early

It is often helpful to introduce topics such as public and private long before the onset of puberty to avoid potential issues later on.

Use appropriate terminology

Rather than teaching one set of terms when children are younger and another set when they are older, it is often helpful to use corrective terminology right from the start. It can be difficult to convince a developing child that the body part they referred to as their “pee pee” for ten years has now become their penis.

Utilize existing resources

Check out your local library, bookstore or health region. Several books have been published to explain puberty and sexuality concepts to children. Although the text/language may not be appropriate—depending on the functioning level of your child—you may be able to utilize the pictures and adapt the language to make it suitable for your child. In addition, it may be helpful to talk about sexuality-related issues with your child’s Physician, Psychologist or other community professionals that have expertise and experience in the area.

Make abstract concepts as concrete and specific as possible

Remember, social-sexual concepts tend to be extremely abstract. Think about the following:

- When and who is it appropriate to hug?
- When and where is it appropriate to remove your clothing?
- When and where is it appropriate to touch, scratch or adjust your private parts?
- When and where is it appropriate to masturbate?
- When is it okay to remove your clothing in front of someone?

There are no straightforward answers to these questions. However, we know that children and youth with developmental disabilities tend to be most successful when concepts are presented in a concrete fashion and rules are as specific as possible. Here are some examples:

- Hugs are only for mom, dad and grandma
- You should only take your clothes off in the bathroom at home with the door closed, in your bedroom with the door closed, in the change room at the swimming pool and at the doctor's office
- You should only touch, scratch or adjust your private parts in the bathroom with the door shut, or in a stall if you are using a public washroom, or in your bedroom with the door shut
- You should only take your clothes off with the following people... (This list will likely vary depending on your child's age, schedule and health status.)

Sexuality issues are further complicated by the fact that everyone brings their own unique perspective and personal belief system into the picture. Our comfort level, values and opinions about human sexuality are shaped by our religion, culture, family background and personal experience. Therefore, before initiating or developing a plan, it is essential to discuss the issue in detail—challenging behaviours, skills to teach, rules to follow—to gain a clear understanding of the implicit rules and values within your family.

Example: Privacy/Modesty

James is a 13-year-boy with ASD. He is nonverbal, but able to use picture symbols to communicate his basic needs. Over the last six months, he has started putting his hands into his pants and masturbating. James' parents are very concerned about this behaviour, as he has pulled down his pants at school and at the mall. A team meeting was held to develop an intervention plan.

Making abstract concepts concrete

James' parents indicated that they were comfortable with him removing his pants and masturbating in his bedroom with the door closed. They were not okay with him doing so in the bathroom as they were worried that he might think it is okay to masturbate in all bathrooms—other people's homes, public washrooms, for example. In this case, an abstract concept—when and where it is appropriate to masturbate—was translated into a concrete rule—masturbation limited to bedroom with door closed.

Clothing

It was noted that James was less likely to touch his penis and pull down his pants when he was wearing pants with zippers. In addition, erections were less noticeable when James was wearing heavy pants. Although he preferred to wear loose fitting clothing with elastic waistbands, such as sweat pants, his parents encouraged him to wear jeans, particularly when he was at school or out in the community.

Visual support

A visual support was developed to remind James not to touch his penis or pull down his pants unless he was in his room with the door shut. When James was observed attempting to touch himself, he was shown the card and directed to his room. When he was at school, his teacher reminded him to wait until he was home.

Reinforcement

Because James found touching himself to be quite pleasurable, it was necessary to develop a reward system to motivate him to refrain from doing so. The system involved the following:

- Setting a timer for one hour and resetting it each time James attempted to touch himself when he was not in his bedroom
- Providing James' with a sticker each time the timer went off
- Providing James with a special snack each time he earned a total of five stickers

Example: Boundaries around Masturbation

Mitchell is a 15-year-old with a developmental disability. Over the last year, he has started to spend a great deal of time in his room masturbating. Mitchell's parents are concerned about this, as it has reached the point that their son is asking to go to his room, rather than spending time with his friends or family.

Consultation

Mitchell's family and Aide consulted the family physician to discuss the amount of time he was spending masturbating. The doctor indicated that, in her opinion, his behaviour was not developmentally appropriate and agreed that intervention was warranted. The family and Aide subsequently met to discuss what they felt was an appropriate time limit for Mitchell.

Making expectations clear

Mitchell was informed that he could spend one hour per day masturbating. It was made clear that he did not have to use the time, but that he could not exceed it. Mitchell's Aide also purchased a timer. Each time he requested to go to his room the timer was started. Sometimes he stayed in his room for the entire hour, while other time he came out after a few minutes. Regardless of how he used the time, Mitchell was allowed a total of 60 minutes of masturbation time per day.

Resources for Teaching Puberty and Sexuality

Here are some resources you might find helpful:

Bourgeois, P. & Martyn K. (2005). *Changes in you and me*. Toronto, ON: Key Porter Books.

Harris, R. (1994). *It's perfectly normal: Changing bodies, growing up, sex & sexual health*. Cambridge, MA: Candlewick Press.

Madaras, L. & Madaras, A. (1983). *The "what's happening to my body?" book for boys*. New York: Newmarket Press.

Madaras, L. & Madaras, A. (1983). *The "what's happening to my body?" book for girls*. New York: Newmarket Press.

Volkmar, F. & Wiesner, L. (2004). *Adolescence and sexuality*. In *Healthcare for children on the autism spectrum: A guide to medical, nutritional and behavioural issues* (pp. 245-260). Bethesda, MD: Woodbine House.

Unit 5

Evaluating Effectiveness

Why is Data Collection Important?

In this website you can learn about the principles of Applied Behaviour Analysis and how they are often used to teach critical skills. But how will you know if your teaching strategies are effective?

The answer is collecting and evaluating data. Data makes it possible to track progress and to make decisions about the effectiveness of our teaching methods.

- When attempting to teach adaptive behaviours, data collection can help you make decisions: What skills to teach—identifying needs, for example
- The best way to teach a skill—based on the child’s learning style and interests/ motivators
- Whether your teaching method is appropriate to the skill level of the child
- Whether your teaching method is effective
- Whether the child is demonstrating progress, gaining skills and/or becoming more independent

It is important to remember that the information you collect should have the following qualities:

- Meaningful
- Measurable
- Manageable

Here is the basic process:

1. Select which skill you would like to teach. If more than one skill is identified, which is often the case, select the skill that will be most meaningful/functional for the child and family.
2. Choose the data collection method best suits the skill you intend to teach. You may want to consider what you hope to achieve with the skill: increasing the frequency, independence or accuracy (i.e., reducing errors).
3. Implement the data collection system and start recording data.
4. Summarize and analyze the data to assess progress and determine if your teaching has been effective.

Data Collection Begins with a Baseline

A baseline is a description of existing conditions, skills, or behaviours to provide a starting point against which progress can be assessed or comparisons made. Baseline data may reflect the current frequency of a behaviour, the

duration it is displayed, the quality or accuracy of the response, or the level of independence displayed by the child or youth. Baselines measure skills or behaviours before interventions are implemented.

Examples:

- For example, A goal for Jill is to eat meals with her family. Baseline data could help to determine how much time she currently spends at the table before teaching strategies are implemented.
- Craig can get dressed independently. However, sometimes he puts his shirt on inside out or backwards. Baseline data can help determine how many times during a week he puts on his shirt correctly.
- Andrew is working on basic money skills and when he buys a snack from a convenience store, he sometimes gives the cashier the incorrect change. His father observes this skill with Andrew and determines the percentage of times Andrew gives the correct change.
- Some days Jill comes to the supper table when asked, but on other days it is difficult to get Jill to comply. Jill's mother wants to gather information to determine what factors are present on the days that Jill is more cooperative.
- Darcy's parents would like her to close the bathroom door when she enters it. During the course of a week, they record the different levels of prompting required—verbal prompt, guide prompt, etc.—to get Darcy to close the door.

It is important to consider how long you would like to collect baseline information. Baselines can vary in length depending on the type of information you are hoping to collect. Data can be collected during a single routine during a day, throughout the day, and can be collected for short or long periods—for a single day or a whole month, for example. For some behaviours, you may want a quick snapshot of information and a single day of data may be enough. For behaviours that are

displayed less frequently, longer baselines may be needed. Be aware that the data may not be particularly meaningful if a baseline period is too short. For instance, the data may not be accurate if the child or youth had an extremely good or extremely challenging day. Conversely, if a baseline period is too long, you may be wasting valuable teaching time.

Finally, make sure you collect the baseline information under conditions that are similar to the teaching conditions.

Different Types of Data Collection Systems

There are many different ways to collect data depending on the behaviour or skill being targeted. For example, frequency is often important when teaching a skill or when reducing challenging behaviours. When teaching skills in the area of daily living, such

- ABC
- Frequency
- Quality
- Duration
- Latency
- Level of Independence—based on a prompt hierarchy

as using a fork and knife, it may be important to gain information about the child's level of independence. At this point, it may be helpful to review some of the more common types of data collection systems.

ABC Recording

ABC stands for Antecedent, Behaviour and Consequences [reference Teaching Strategies Cluster in Teaching Adaptive Behaviours Unit]. Although this unit focuses on the teaching of adaptive behaviour, it is worth mentioning that ABC data recording is a common and essential method of gathering

information about the function of challenging behaviours.

ABC recording includes documenting the setting or events that precede a target behaviour, the behaviour itself, and the consequences which follow the behaviour.

ABC data recording is used when you want to answer the following questions:

1. When and where a behaviour typically occurs?
2. Under what circumstances does the behaviour typically not occur?
3. What is going on in the environment when the behaviour occurs?
4. Who is typically involved with or near to the child when the behaviour occurs?

ABC data recording helps determine what conditions need to be present in order for a behaviour to most likely occur. For example, ABC data may reveal Jill is more likely to remain seated at the supper table when the lights are dimmed and her family speaks with a quiet tone of voice.

Later, we will discuss “playing detective” and how ABC recording can help identify what is causing or maintaining challenging behaviour, which then helps us to change or reduce that behaviour.

Frequency Recording

Frequency recording involves adding up the number of times a child displays a specific behaviour or skill during a predetermined period—a day, week, month, or during a specific activity like a morning at preschool or a swimming lesson, for example. You may choose to use frequency recording if you want

to see how often a child displays a certain skill, such as how often a child looks left and then right before crossing the street. This information can then be used to determine what skills need to be worked on and if progress is evident.

The data is summarized by keeping a running tally and then calculating an hourly, daily or weekly average.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
IIII I	III	IIII	III	IIII	IIII	III

Daily average = $28/7$ or 4 per day

Here is an example of frequency baseline:

William tends cry when he gets bored with a task. Therefore, his parents thought it might be helpful to teach him to request a break rather than cry. Before developing a teaching plan, his parents wanted to gain information about how often William currently requests a break.

INSTRUCTIONS: Please record data—using a tally mark—each time William requests a break. Data should be recorded for the dates noted below.

Date	Frequency Count	Total
June 1, 2008		
June 2, 2008		
June 3, 2008		
June 4, 2008		
June 5, 2008		
	Grand Total:	

Quality Recording

Quality recording refers to data that is recorded to indicate a child’s success during a specific task or activity. This type of data collection can be especially useful when teaching a skill that is made up of several different steps, like tooth brushing, or for teaching discrimi-

nation skills, such as identifying the dirty parts when wiping a table, or being able to tell the difference between a dime and a nickel. The data is summarized by calculating the percentage of correct versus incorrect responses.

Here is an example:

It is unclear if Sally is able to label and identify basic colours. Before developing a teaching plan, her parents wanted to gain more information about Sally’s skills.

INSTRUCTIONS: Please record data, using a “+” for correct and a “-” for incorrect, for each of the following over five days with randomized presentation of the colours:

Date		
Colour	Receptive Identification (“Show me the...”)	Expressive Label (“What colour is it?”)
Red		
Blue		
Green		
Yellow		
Orange		
Total Correct:		

It is often necessary to calculate the percentage of correct responses—number of correct responses/total number of responses for comparison purposes.

Duration Recording

Duration recording is used to indicate the length of time a child engages in a particular behaviour or is able to perform a particular skill. Here, the data is usually summarized by calculating the average length of response/behaviour over a number of trials. Duration recording is used when the primary concern is the length of time a behaviour occurs. This is important because sometimes the frequency alone doesn’t tell the whole story.

Jill sat at the table with her family a total of 21 times in April and 19 times in May. However, her family reports her skills have improved. How can this be? The mystery was solved by looking at the data from a duration baseline. This data revealed that Jill sat for an average of 3 minutes in April, but an average of 8 minutes in May. No wonder the family thought that Jill’s skills had improved.

Here is the duration baseline that was used:

INSTRUCTIONS: Please record data regarding the length of time Jill remains seated at the table during supper.

Date	Leangth of time child remained seated
May 1, 2008	
May 2, 2008	
May 3, 2008	
May 4, 2008	
May 5, 2008	
Grand Total:	

Latency Recording

Latency recording involves measuring the time elapsed between the presentation of a stimulus, such as a verbal instruction to put on a coat, and the child’s response to that request. Latency is the time between the request and the action. Latency recording is used when the goal is to improve reaction time. Some children can perform a task independently and efficiently once they get started, but it can take a long time to get started.

For example, Chynna can change into her pajamas, wash her face and brush her teeth

all by herself. However, it takes her a long time to start the process when she is asked to get ready for bed.

Often, using reinforcement or practicing a skill until it becomes an extremely quick response may help improve latency. You should also be aware that tracking latency might not be appropriate for all children—those who have a biological processing delay, for example.

Prompting was reviewed in more detail earlier, but you may wish to refer to the chart below as a reminder:

Type of Prompt	Description	Example
Full Physical Assistance, Full Prompt or Hand over Hand Assistance	The child needs physical assistance to complete a task. The Aide will use hand-over-hand prompting to ensure the correct response occurs	When asked to identify a cup, the Aide takes one of Jill's hands, and places it on a cup.
Partial Physical Assistance or Partial Physical Prompt	The child needs partial physical assistance to complete a task. The Aide will use physical prompting to start the action or complete the action to ensure the correct response occurs	When asked to identify a cup, the Aide takes one of Jill's hands, and moves it towards the cup.
Full Model	The entire response is modeled for the child.	When the Aide tells Jill to clap, she claps at the same time as she gives the instruction.
Partial Model	Only part of the response is modeled for the child.	When the Aide tells Jill to clap, she holds her hands out, palms towards each other, but does not clap.
Full Verbal Model/ Prompt	In addition to the instruction, the desired response is modeled	When teaching the label "cup", the Aide asks, "What is it? Cup."
Partial Verbal Model/ Prompt	Only part of the desired response is modeled	When teaching the expressive label "cup", the Aide asks, "What is it? C__."
Gesture	A gesture is provided to the child to prompt the desired response	When asked to identify the cup—"Find cup,"—the Aide pushes the cup towards Jill.
Sign language	A sign is provided to the child to prompt the desired response.	When asked to sit down, the Aide also signs "sit down" to Jill.

Type of Prompt	Description	Example
Proximity or Positional Prompt	When teaching, the target is placed in a specific location to prompt the desired response.	Before Jill is asked to identify a cup, the cup is placed closer to Jill than other items.
Point	The Aide points to the target to prompt the desired response.	When Jill is asked to identify a cup, the Aide points to the cup.
Visual Cue	A visual cue—photo or picture—is provided to prompt the desired response.	When Jill is asked to identify the cup, the Aide shows her a picture of a cup.

When evaluating a child’s level of independence, you can approach the data in a few different ways:

Step-by-Step Analysis:

Step-by-step analysis helps us see what specific parts of a task the child needs the most help with learning and also lets us know what steps have been mastered. Therefore, it is useful for identifying what steps to focus on teaching, and for avoiding over-prompting. This method records the level of independence or prompting required on each step of a task; for example, recording the prompting required for each of the six steps associated with a particular task. For example, it was decided that the best way to teach Jill to hang her coat on a hook was to break the task into four steps. The level of prompting she required is recorded for each of the four steps:

Step	Level of Prompting Required
Grab collar of coat with both hands	Full physical assistance
Turn open side away from body	Independent
Place collar area on hook	Point prompt
Release coat	Independent

Specific Step Analysis

This involves recording the level of prompting required to complete a specific step in the task analysis.

Step: Grabbing the collar of coat with both hands	
Trial	Level of Prompting Required
1	full physical assistance
2	partial physical assistance
3	point prompt
4	partial physical assistance
5	point prompt

Most Intrusive Prompting Required

This involves identifying the most intrusive prompt required when a child or youth is assisted to complete the steps of a task. The most intrusive prompt—or highest level of assistance— used is recorded on the data sheet.

Date	Most intrusive prompt required to complete the task analysis
June 1	full physical assistance
June 2	full physical assistance
June 3	partial physical assistance
June 4	full physical assistance
June 5	partial physical assistance

When teaching a new skill for the first time, you may want to use a more intrusive level of prompting so that the child knows exactly what is expected. This helps to ensure that the child experiences success and avoids errors.

Your Turn

As you can see, teaching a skill that involves a number of steps can be complex. This is why it is important to become familiar with prompt hierarchies. Below is another example of a level of independence data sheet. What was the most intrusive level of prompting used on Monday? What about Tuesday?

Step/Task	Level of Prompting Required				
	Monday	Tuesday	Wednesday	Thursday	Friday
Turns on Cold Tap	point	independent			
Turns on Hot Tap	point	point			
Wets Hands	full physical	partial physical			
Pushes Down on Pump	independent	independent			
Catches Soap on Palm	independent	independent			
Rubs Soap on Palms	full model	full model			
Rubs Soap on Backs of Hands	partial physical	full model			
Rinses Hands Thoroughly	verbal	independent			
Turns Off Hot	independent	independent			
Turns Off Cold	independent	independent			

Data Analysis and Data-Based Decision Making

Depending on the behaviour or skill being measured, the data may be summarized using daily or monthly averages, totals/whole numbers or percentages.

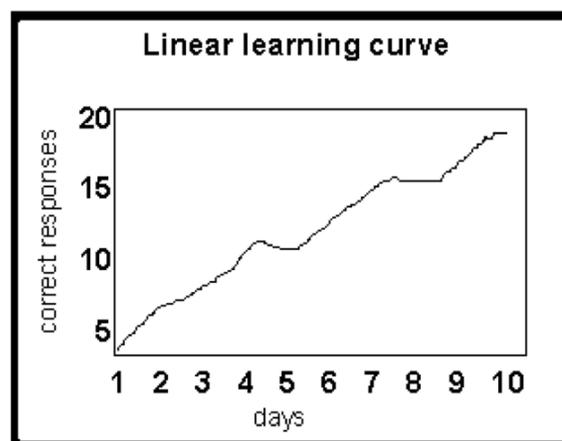
Baselines can be completed in a variety of different ways. In some cases, it may be possible to baseline a particular skill or behaviour before any intervention/teaching takes place—a true baseline. In other cases, baseline data may be collected intermittently during teaching to track progress.

Blank spaces on data sheets can be misinterpreted and have the potential to influence the overall results. Therefore, it is often helpful to write “absent” or “none” rather than leave a space blank. Keep in mind that miss-

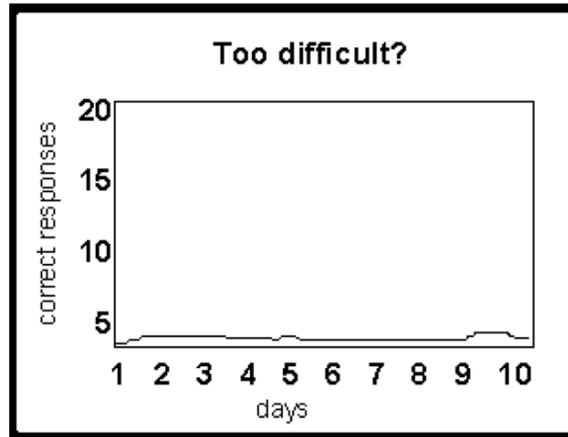
ing data may affect the calculation of daily or monthly averages.

Based on what you know about the child, you should have some idea what you expect, or hope, progress will look like. Once your data is collected, it is important to determine if child’s progress is consistent with your expectations. Each child and youth has a unique learning pattern. Progress may be slow but steady, it may be immediate and dramatic or it may be minimal until something clicks with the child. Looking at trends and patterns can also help you decide whether your teaching method needs to be modified or adapted.

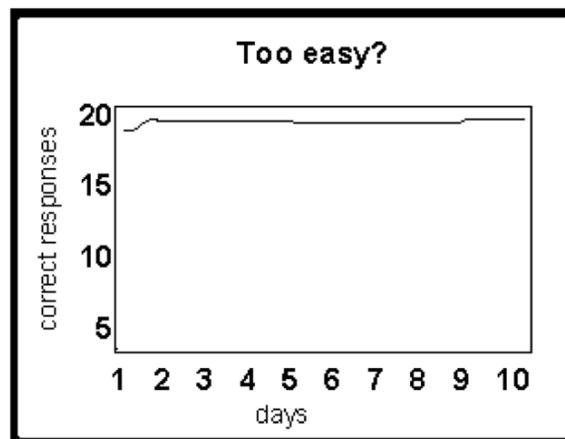
When teaching a new skill, the best case scenario is that the child’s progress is linear, as illustrated in the graph below. It should be noted that a linear learning curve is an ideal. In reality, progress is often inconsistent as evidenced by peaks and valleys in the graph.



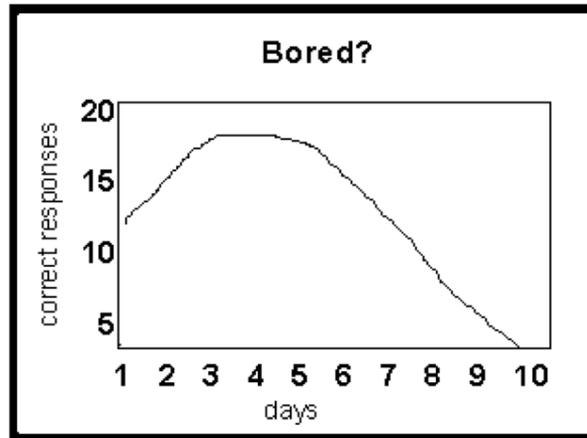
If progress is minimal for an extended period, this may suggest that the teaching method is ineffective or the goal is too difficult—see graph below. If this is the case, you may need change different aspects of how you are teaching; for example, simplify your procedure, increase the level of prompting, increase reinforcement, modify the goal, etc.



If progress is rapid, it is possible that the child is a quick learner and/or the selected goal is too easy—see graph below. In either case, the next step would be to establish a new goal or increase expectations; for example, expect the child to perform the task more independently.



If a child initially makes steady progress, but then displays a decline in skills, it may suggest that he or she is getting bored. If this is the case, you may need to use a different type of reinforcement, introduce new materials, or look for a different way to teach the skill.



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3

Module 3: Managing & Minimizing Challenging Behaviour

Unit 1: Understanding the Function of Behaviour

- Topic 1:** Importance of understanding the function of behaviour
- Topic 2:** Using ABC to understand the function of behaviour
- Topic 3:** Functional behaviour assessment
- Topic 4:** Behaviour: Identify & define the behaviour
- Topic 5:** Antecedents: Identify antecedents that predict the behaviour
- Topic 6:** Consequences: Identify consequences that maintain the behaviour
- Topic 7:** Possible functions of challenging behaviours
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- Topic 9:** Escaping or avoiding something
- Topic 10:** To gain access to something tangible
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Unit 5: The Key Elements of a Behaviour Plan

- Topic 1:** The importance of behaviour support plans
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- Topic 3:** Developing a behaviour support plan
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- Topic 1:** Intervening when challenging behaviours are displayed
- Topic 2:** What can I do ahead of time to promote safety?
- Topic 3:** What can I do while the child/youth is acting out to deescalate the stimulation & promote safety?
- Topic 4:** Physical intervention
- Topic 5:** What can I do after the incident to promote safety?

Unit 6: Evaluating Behaviour Support

- Topic 1:** Data collection
- Topic 2:** Frequency data
- Topic 3:** Duration data
- Topic 4:** Level of independence data
- Topic 5:** Evaluating effectiveness
- Topic 6:** Revising your plan



Unit 1

Understanding the Function of Behaviour

Importance of Understanding the Function of Behaviour

The challenging behaviours that are displayed by children with disabilities have a purpose that can be of great importance to the child. In spite of popular belief, children rarely misbehave just for the sake of it. Almost all behaviour occurs within a particular context and serves a specific purpose. Keep in mind that children and youth need adults: they depend on them for the fulfillment of their physical and emotional needs. If children or youth have difficulty getting their wants and needs met in more typical or traditional ways, they may resort to the easiest way they know – through behaviour.

Children with complex disabilities often have a limited repertoire of skills; their desire to meet their needs or achieve certain outcomes may result in behaviours that are challenging to those around them. It is important to note that children and youth will only change their behaviour when it is clear that (1) the behaviour that they have used in the past is no longer effective and (2) a different response will more effectively or efficiently result in the same outcome. Identifying the function of behaviours is critical to developing a Behaviour Support Plan to address the challenging behaviours.

Food for Thought

You are playing with your child, and are momentarily distracted when the phone rings. Suddenly, your child screams.

What do you do?

Ultimately, what you do will determine whether your child is more likely to scream in the future under the same conditions. Understanding the function of the behaviour (why your child screamed) will help you to determine what you should do.

An example:

Sean is sitting at home watching TV. His mom comes into the living room and lets him know that supper is almost ready. When she comes back and tells him to turn off the TV, Sean starts to scream. If his mom lets him continue watching TV and he stops screaming, it is possible that he was trying to maintain access to a preferred activity (i.e., watching

TV). If the TV stays on, but Sean continues to scream, it is possible that he is trying to avoid having dinner. Note that the behaviour may be the same, but the function is very different (i.e., trying to access a preferred activity versus trying to avoid a less preferred activity).

Guiding Principles from Research and Evidence-based Practice

Behaviour Support Plans, which are developed with the support of your child's entire team, should take into consideration the following principles and evidence-based best practices:

**adapted from Special Education Council of the Alberta Teachers' Association (2007).

BOATS: Behaviour Observation Assessment Teaching Strategies (2nd Edition). Edmonton, AB.

Behaviour is learned and therefore can be unlearned.

Bobby is 9 years old and does not communicate verbally. When he was younger, he would often pinch the arm of his mother to indicate that he needed a break. He learned that this was an effective way to end a task. He has since been taught to hand his mother a "break" picture symbol rather than pinching her.

Each child is unique and therefore the Behaviour Support Plan should be based on the perceived function of his or her behaviour.

Amy is 12 years old and can speak in full sentences. Amy also pinches those around her. Functional Behavioural Analysis revealed that she was motivated by the attention of others, even if their reaction was negative. Amy learned that people always paid attention to her when she pinched them. Now Amy's parents have made a concerted effort to modify the environment (e.g., by wearing long-sleeved shirts) to make it easier for them to ignore the behaviour.

Although both Amy and Bobby display the same behaviour – pinching – they are at different developmental and skill levels, and are motivated by different needs.

Behaviour serves a need, purpose or function.

As we learned in the two previous points, the behaviour of pinching others was a way to end a task for Bobby, while the same behaviour was used by Amy to gain attention.

Behaviour is influenced by the type of reinforcement or consequence received after the behaviour occurs.

Amy learned that pinching others almost always resulted in that person paying attention and saying something to her.

When Bobby was younger, he learned that pinching was an effective way to end a task.

Observational data is generally needed to help identify the function of challenging behaviour.

A Behavioural Aide will assist you in collecting data to analyze and evaluate the effectiveness of a Behaviour Support Plan.

Understanding the function of behaviour helps one to identify alternative and more appropriate behaviours that serve the same purpose and, therefore, should be taught to the child.

For example, teaching Bobby to use a “break” picture symbol was an appropriate and effective intervention for him, but it wouldn’t be effective for Amy.

Altering the child’s environment may be required.

Bobby’s mother knows that he can become easily distracted and, by reducing distractions, he is better able to learn. For example, when teaching Bobby the skill of stringing beads or stacking blocks, the table is clear of distractions and Bobby is only given a few blocks at a time. Bobby’s mother learned early on that putting dozens of blocks in front of him would result in tantrum behaviour.

Likewise, Amy’s parents learned that wearing long sleeve shirts reduced the likelihood of getting pinched.

Altering the manner in which information is communicated and taught may be required.

For example, Bobby has difficulty processing and understanding verbal communication. His mother routinely uses the visual picture schedule developed by his aide, to increase his level of cooperation and reduce challenging behaviours.

Data collection is used to guide practice.

Data collection helps your child’s team to determine what motivates behaviour and assess the effectiveness of teaching methods (i.e., replacement skills) and Behaviour Support Plans.

The first step in understanding a child's behaviour is to determine whether there is a medical reason (i.e., is the child ill)? Although the child's behaviour may have meaning ("I'm sick"), more important is the resolution of any illness. For example, children may scream when they have an ear infection.

Using ABC to Understand the Function of Behaviour

Now that you know you need to understand the meaning behind challenging behaviour, how do you go about doing that? Understanding "why" behaviour occurs involves looking at the various aspects of the challenging behaviour (what precedes it, what the behaviour is, and what happens afterwards) and trying to identify why it might be occurring. This is true for most behaviour, regardless of whether we are talking about desirable or undesirable behaviours. We need to identify the "ABCs":

A is the Antecedent, or the activity or event, that immediately precedes the child's behaviour,

B is the Behaviour of the child, and

C is the Consequence that the child experiences as the result of the behaviour.

When behaviour is paired with a consequence that is positive (from the perspective of the person engaging in the behaviour), it increases the likelihood that, under the same circumstances (i.e., antecedents), the behaviour will occur again.

Anything that increases a behaviour, making it occur more frequently, making it stronger, or making it more likely to occur, is termed a reinforcer. Remember, it is the perspective of the child or youth engaging in the behaviour determines if something is reinforcing – our opinion does not matter.

Functional Behaviour Assessment

There is no specific "tool" that can be used to assess behaviour. Rather, understanding the function of behaviour is a process. This process is called a Functional Behaviour Assessment.

Functional Behaviour Assessment is a systematic process of identifying the ABCs:

- the events that reliably predict (are associated with) the occurrence and non-occurrence of those behaviours are called Antecedents,
- challenging Behaviours, including the operational, or concrete, definition of the challenging behaviour(s),
- a description of the Consequences or events that maintain those behaviours across time.

When you're trying to understand challenging behaviours, it's helpful to start with B, understanding the behaviour first, and then identifying the antecedents and consequences associated with that behaviour.

Identify and Define the Behaviour

Generally speaking, the first step in this process is observing your child. While we often assume that watching the child in situations where challenging behaviour typically has been reported is important, it is also important to watch the child in situations where the behaviour is rarely or never displayed. Observing your child under a variety of conditions allows you to describe:

- **what** the behaviour looks like,
- **with whom** the behaviour occurs (or does not occur),
- **when** the behaviour occurs (times of day, different activities) and when the behaviour does not occur (including setting events),
- **where** the behaviour occurs,
- **how** people around the child respond to the occurrence of behaviour, and
- the child's needs, interests and skill set.

Antecedents: Identify Antecedents that Predict the Behaviour

The second step in assessing challenging behaviour is to identify the events or antecedents that reliably predict occurrence and non-occurrence of the challenging behaviour.

Analysis of antecedents considers all of the things that come before the behaviour, including what occurred immediately before the behaviour, as well as events that led up to the antecedent.

Antecedents

All behaviours follow an event or an antecedent (or series of events/antecedents). To understand behaviour effectively, it is critical to be able to describe what happened in your child's world prior to the behaviour occurring. This includes:

- **Where** did the behaviour occur (single environment, multiple environments)?
- **What** was happening (noise level, change in routine, etc.)?
- **Who** was present?
- **What** were the individuals (child, peers, Aide) doing?
- **When** did the behaviour occur?

Knowing what precedes a behaviour gives you an opportunity to intervene and stop the behaviour from occurring in the first place (i.e., implement proactive strategies). If we know what triggers behaviour, it helps in the development of a plan for teaching alternative behaviours.

An example:

In the past, when Dorothy wanted to escape from a difficult task, she would get up from the table and try to leave the room. Her team decided that they would allow her to “ask for a break”. They taught Dorothy that giving an adult a picture symbol (“break” card) would result in her being allowed to sit on the floor away from the table to play with some neutral toys for two minutes. As well, her team used shaping to teach her to use this picture symbol at the table when they felt that she needed a break. That is, when Dorothy would stand up, they would prompt her to ask for a break. Now, she stands up each time before she “asks for a break”.

Food for Thought

One morning, you press your snooze button one too many times and you end up leaving your house a bit later than usual. The roads are covered in fresh snow. On your drive to work, you spill coffee because the lid is not on tightly. It seems like every light that you hit is red, and no matter what lane you are in, it is the slowest. You get to work and you have to park far away, forcing you to walk a long way on slippery sidewalks. Once you get in, the phone is ringing, but by the time you get your door unlocked, it stops ringing. You sit down at your desk. Suddenly, your least favourite co-worker shows up at your door and comments, “Oh, you made it in today”. How do you respond? It is possible that how you respond to that comment (the “antecedent”) may be different on that day compared to a day when the morning routine has been “good” (e.g., you have a great night’s sleep, the weather is great, you have a great drive in to work and your favourite co-worker brings in muffins).

Consequences: Identify Consequences that Maintain the Behaviour

The third step in assessing challenging behaviour is to identify the consequences or events that maintain challenging behaviours over time. For a behaviour to become established (i.e., to become a pattern of behaviour), it must be reinforced in some manner. It is the consequence that has the biggest impact on whether challenging behaviour occurs again under the same or similar circumstances.

We are trying to determine what is

reinforcing the challenging behaviour. Remember, is the perspective of the individual engaging in the challenging behaviour that determines whether the consequence is reinforcing. Consequences can be natural (e.g., you climb up on a cupboard and get hurt when you fall down; you climb up on a cupboard and obtain a snack) or may occur as the result of another person responding to your behaviour (e.g., you tell a joke and people laugh; you

tell a joke and get silence).

Consequences are things that motivate the child to engage in the challenging behaviour – they are one of the most critical elements in our assessment of challenging behaviour and understanding why that behav-

our occurs. It is ultimately what the behaviour results in – allowing the child to escape or avoid a task, gain attention, obtain an item or activity or engage in self-reinforcing activity – that, in turn, causes the challenging behaviour to occur again because it is reinforced.

Examples

Consequence	Reinforces the function
Behaviour results in the child being removed from the classroom	The child was engaging in the behaviour to avoid doing a math assignment
Behaviour results in the child being given a snack	The child was trying to obtain food
Behaviour results in the child getting a hug	The child was trying to get attention from his mother
Behaviour results in the child losing access to a toy	The child was trying to avoid playing with the toy
Behaviour results in the child getting to leave the gym	The child was trying to get away from the echoing noise

Possible Functions of Challenging Behaviours

Challenging behaviour may serve different functions. Understanding the function of the behaviour may help to determine how to manage the behaviour.

Food for Thought

Part 1

Take a look at the following list and decide what these words best describe, or have in common:

- Hitting
- Kicking
- Screaming
- Biting
- Scratching
- Non-compliance
- Running away
- Spitting
- Pinching
- Head-banging

Your immediate response to the list may be something like the following:

- “Behaviour”
- “Bad”
- “Wrong”
- “Aggression”
- “Violence”
- “Negative behaviours”
- “Challenging behaviours”
- “Unacceptable”

Part 2

Now look at the first list again – but this time, try to put yourself in your child’s shoes. If you were a child with a developmental disability, why might you display one or more of these behaviours?

From the perspective of adults, these behaviours are often viewed as problems that we need to eliminate. However, from the child’s perspective these behaviours are not problems: they are solutions to a problem. Now we are going to look at some of the most common functions of challenging behaviour.

Attention seeking

A common function of challenging behaviour is to gain attention. Often, it is more challenging for children with disabilities to gain the attention of adults and peers because they have limited communication skills. Therefore, they gain attention using the skills that they have, and the resulting behaviour is

often viewed as challenging from the perspective of people in their environment.

Attention-seeking behaviours are generally things that the child has learned will result in others talking to them or interacting with them.

Depending on the child or youth, attention-seeking behaviours may include:

- Vocalizing: screaming, yelling, crying, swearing, protesting, joking, etc.
- Unsafe behaviours: standing on tables, climbing on shelves, running when unsafe to do so, playing with unsafe materials, smearing feces, etc.
- Developmentally inappropriate behaviour: babbling when they can speak, crawling on the floor when they can walk, stripping off clothes, thumb sucking, etc.
- Aggression: biting, hitting, kicking, destruction of property, spitting, etc.

An example:

Jefferson is a 5-year-old child with autism. He has just learned to have bowel movements in the toilet. His mom used to spend a lot of time in the bathroom with him, encouraging him to urinate and have bowel movements in the toilet. Jefferson now appears to be “toilet trained” as he has been initiating on his own. Mom is also trying to withdraw reinforcement, which has been a small chocolate. On this occasion, while in the bathroom, Jefferson gets some feces on his hand. He comes out and shows it to his mom. She takes him back to the bathroom and has him wash his hands. She then praises him for pooping in the toilet and gives him a chocolate.

Could Jefferson’s mother be (inadvertently) reinforcing his behaviour by giving him attention?

Antecedents for attention-seeking behaviours are often difficult to determine. Sometimes it is that someone else is getting attention, or the child is simply not getting any attention at a particular time. Due to limited communication skills, the child is unable to “tell” someone that she wants attention, praise or other forms of positive reinforcement.

Escaping or avoiding something

Another common function of challenging behaviour is to avoid engaging in an activity, escape a particular environment, or avoid interacting with someone. It is often more challenging for children with disabilities to protest effectively because they have a limited skill set. Therefore, they protest

using the skills that they have, and the resulting behaviour is often viewed as challenging from the perspective of people in their environment. Escape-motivated behaviours are generally things that the child has learned will often result in them being able to avoid a task, situation or person.

Depending on the child or youth, escape-motivated behaviours may include:

- Vocalizing: screaming, yelling, crying, swearing, protesting, joking, etc.
- Unsafe behaviours: standing on tables, climbing on shelves, running when unsafe to do so, playing with unsafe materials, smearing feces, etc.
- Developmentally inappropriate behaviour: babbling when they can speak, crawling on the floor when they can walk, stripping off clothes, thumb sucking, etc.
- Aggression: biting, hitting, kicking, destruction of property, spitting, etc.

Does this list seem familiar? It should, because it is similar to the set of behaviours listed for attention seeking.

An example:

Jefferson is a 5-year-old child with autism. He has been working on toilet training for a while, but still has bowel movements in his pull-up, which he does not like. One day, Jefferson has had a bowel movement in his pull-up, and it is uncomfortable. It does not help that at the same time, he is being asked to sit at circle time, which he often tries to escape from by standing up, but is consistently redirected to sit down again by his Aide. When his Aide is turned the other way, Jefferson tries to relieve the uncomfortable feeling by reaching into his pull-up. He pulls out some feces, and wipes the feces on his shirt (he is fast). When his Aide turns back, his hand and shirt is covered in feces. She immediately directs Jefferson to the bathroom to get him cleaned up.

Could Jefferson's Aide be (inadvertently) reinforcing his behaviour of smearing by allowing him to leave an activity that he wants to leave?

Antecedents for escape-motivated behaviour are often signals that indicate a change is about to occur, or an instruction being given. If the challenging behaviour is effective in escaping the unpleasant event/activity, it is likely that the behaviour will occur again when the antecedent event occurs in the future.

To gain access to something tangible

Another common function of challenging behaviour is to gain or retain access to a desired item, object or activity. As we know, it is more challenging for children with disabilities to request what they want/

need. Therefore, they try to get their needs met using the skills that they have, and these are often viewed as challenging from the perspective of people in their environment.

Depending on the child or youth, tangible-seeking behaviours may include:

- Vocalizing: screaming, yelling, crying, swearing, protesting, etc.
- Aggression: grabbing, biting, hitting, kicking, destruction of property, spitting, etc.
- Unsafe behaviours: climbing on shelves, smearing feces, running when unsafe to do so, playing with unsafe materials, etc.
- Developmentally inappropriate behaviour: babbling when they can speak, crawling on the floor when they can walk, stripping off clothes, thumb sucking, etc.

Does this list seem familiar? It should, because it is similar to the set of behaviours listed for attention-seeking and escape-motivated behaviours.

An example:

Jefferson is a 5-year-old child with autism. He has been working on toilet training for a while, but still has bowel movements in his pull-up, which he does not like. One day, Jefferson has had a bowel movement in his pull-up, and it is uncomfortable. He puts his hand down his pull-up, and he gets feces on his hand. Jefferson wipes the feces on the table and on his shirt. His mother comes into his room and discovers him sitting with feces smeared “all over”. Her immediate response is to take Jefferson into the bathroom, strip him down, and fill the tub with soapy water (one of his favourite things).

Could Jefferson’s mother be (inadvertently) reinforcing his behaviour of smearing by giving him a bubble bath?

Antecedents for tangible-seeking behaviours are, again, often less obvious. Behaviours can be triggered when someone else is getting the thing the child wants, when an item is being removed from his possession, or when access to the item has been limited for a certain period of time.

Sensory-seeking behaviours

Challenging behaviours are not always directed towards others. Some behaviours are self-reinforcing, calming or entertaining to the child. In addition, some children with disabilities experience the world differently, from a sensory perspective. They are often remarkably sensitive to lights, sounds and touch, and may be more prone to being over- or under-stimulated.

Some stereotypical behaviours do convey meaning (e.g., I'm tired, bored, need a break, avoiding something) and are sometimes learned behaviours. Stereotypical behaviour can interfere with the child's ability to engage in more adaptive behaviours or with their inclusion in community activities. We all engage in stereotypical behaviours. Most of us have a huge repertoire of behaviours (e.g., chewing on pens, playing with our hair, wiggling our

legs under the table, chewing gum) that we engage in to meet our needs or to change our level of arousal. Most children with disabilities do not respond to social cues that let most of us know that we are engaging in unusual behaviour.

Sensory-seeking behaviours are generally things that the child has learned meets a certain need. Another common function of challenging behaviour is to gain or retain access to a desired item, object or activity. As we know, it is more challenging for children with disabilities to request what they want/need. Therefore, they try to get their needs met using the skills that they have, and these are often viewed as challenging from the perspective of people in their environment.

Depending on the child or youth, sensory-seeking behaviours may include:

- Vocalizing: screaming, humming, babbling, etc.
- Aggression: hitting, biting, kicking, destruction of property, spitting, etc.
- Unsafe behaviours: climbing on shelves, smearing feces, running when unsafe to do so, playing with unsafe materials, etc.
- Developmentally inappropriate behaviour: crawling on the floor when they can walk, stripping off clothes, thumb sucking, etc.

Does this list seem familiar? By now you should get the picture that the same behaviour can serve multiple functions.

Food for Thought

Think of things that you do when you are feeling anxious (e.g., you are taking a test). What helps you to calm down? Do you fidget with your hands or feet, drink water, or take a walk? As well, what are some things that you do when you are feeling under-aroused? Do you fidget with your hands or feet, drink water, or take a walk? Remember, for some individuals, these different activities are arousing, while for others they are calming.

An example:

Jefferson is a 5-year-old child with autism. He has been working on toilet training for a while, but still has bowel movements in his pull-up. One day, he is playing with his hands inside of his pants and he come across feces. Since Jefferson enjoys a variety of textures such as Play-doh, oatmeal and shaving cream (really, anything with a mushy consistency), he pulls out some of the feces. Jefferson then proceeds to smear the feces on the wall in his bedroom. In addition to feeling good, it looks pretty interesting as well. When his mom comes to check on him, she immediately directs him to the bathroom to get him cleaned up.

What could be reinforcing Jefferson's behaviour of smearing?

How Do I Choose Which Behaviour to Focus On?

When dealing with many challenging behaviours, it is often difficult to decide what should be the focus. While there are a number of criteria that may be used to determine what behaviour(s) to focus on, the following should be considered:

- Is the challenging behaviour dangerous and/or destructive – do the behaviours pose serious threat to the child and those around her?
- Is the challenging behaviour disruptive – do these behaviours interfere with learning, being included in everyday activities, or are they behaviours that could become destructive if left unchecked?
- Is the challenging behaviour distracting – do these behaviours interfere with social acceptance into groups, are they causing damage, could they become more disruptive or destructive if left unchecked?
- Who is impacted by the child's challenging behaviour and to what extent are their activities impacted?
- Does the child's challenging behaviour significantly interfere with activities of daily living?
- Can the child's challenging behaviour be addressed using behavioural strategies?

You might want to consider the severity of behaviour as a continuum and think about the behaviours you might see in the child, as demonstrated in the following chart:

Severity of Behaviour					
Low level ----->High level					
Who is impacted	Behaviour is confined only to the observed child and does not pose any threat to themselves	Behaviour disrupts others in the child's immediate area	Behaviour disrupts everyone in vicinity	Behaviour disrupts other areas of the home or common areas of the home	Behaviour causes or threatens to cause physical injury to self or others
Examples	<ul style="list-style-type: none"> •refusal to follow directions •scowling •crossing arms •pouting •muttering under his breath •crying •self-stimulation 	<ul style="list-style-type: none"> •scattering toys •grabbing items •using inappropriate language or tone •crying •self-stimulation 	<ul style="list-style-type: none"> •throwing objects •yelling or screaming •destruction of materials •crying 	<ul style="list-style-type: none"> •throwing objects •yelling or screaming •destruction of materials •crying 	<ul style="list-style-type: none"> •physically aggressive behaviours •verbal aggression •self-injurious behaviours
Might impact	<ul style="list-style-type: none"> •ability to participate in home, school, community •social success: friendships, groups, social acceptance 	<ul style="list-style-type: none"> •ability to participate in home, school, community •social success: friendships, groups, social acceptance 	<ul style="list-style-type: none"> •ability to participate in home, school, community •social success: friendships, groups, social acceptance 	<ul style="list-style-type: none"> •ability to participate in home, school, community •social success: friendships, groups, social acceptance 	<ul style="list-style-type: none"> •ability to participate in home, school, community •social success: friendships, groups, social acceptance

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Unit 2

Avoiding & Preventing Challenging Behaviours: Proactive Strategies

Proactive Strategies to Increase Positive or Adaptive Behaviours

Challenging or “problem” behaviour typically occurs when environmental stressors or expectations exceed the child’s capacity to respond in an adaptive manner. Communication skills, flexibility, frustration tolerance/ coping and other adaptive behaviours often need to be specifically taught if you hope to reduce or eliminate problem behaviour.

The frequent and intentional use of positive behavioural supports is critical when supporting a child who displays challenging behaviour. In this unit, we will review a variety of different proactive strategies.

Proactive strategies alone won’t teach skills, but they do reduce problem behaviours and allow your child to be calm or focused enough to learn more appropriate replacement skills. For example, Adis is a youth who

enjoys going to hockey games and movies with his Father. However, despite greatly enjoying the activities, he would often have a tantrum, screaming and swearing within minutes of entering a hockey arena or movie theatre. This would cause them to have to leave and resulted in even more problem behaviours. It was identified that Adis can become easily overstimulated in crowds. One effective proactive strategy was to enter the location a little earlier or a little later than the majority of movie goers or hockey fans. This resulted in his being calm enough to work on other skills while at the hockey game (such as using his words to describe when he needed a “break” or engaging in calming strategies like taking some deep breaths if he got too excited).

In order to eliminate a challenging behaviour, it is often necessary to teach an adaptive skill that serves the same function for the child (i.e., a replacement skill or behaviour). Although this is covered in the Teaching Adaptive Skills unit, it is important to quickly review some key points. Children with developmental disabilities may not learn from past mistakes, and many critical skills may need to be specifically and systematically taught. Below are some of the critical skills that often need to be taught:

- Communication skills (e.g., requesting, rejecting and making choices)
- Social skills (e.g., greetings, concept of personal space, sharing, turn-taking)
- Coping skills (e.g., frustration tolerance, coping with change, relaxation techniques)

Proactive strategies generally fall into two categories:

1. Those that involve adapting the environment
2. Those that require us to adapt our own behaviour (how we interact with the child or youth)

You might be wondering, “If I change the environment of the child, and then change my behaviour, how does that prepare him for the real world? After all, the real world has rules and consequences.” However, getting into power struggles and exerting your will doesn’t help to prepare the child for the real world either. This is because power struggles model conflict and inflexibility – two characteristics that we do not want the child to adopt.

Traditional discipline methods seldom work with children with developmental disabilities, and they may not learn from their mistakes or by observing the behaviour of their peers. Our role is to support the child, not simply to enforce rules. Our job is to provide him with the skills he needs to be as independent as possible and to reach his full potential, whatever that may be.

Environmental Factors to Consider to Reduce Challenging Behaviour

Challenging behaviours can often be reduced or eliminated by making changes to the child’s physical environment.

Specific challenging behaviour often occurs under certain conditions. This can include certain locations, interactions with certain individuals, or other environmental triggers. However, this doesn’t mean that the

entire house needs to be turned upside down in order to ensure that your child does not come into contact with “triggers”. Rather, it often involves setting up the environment so that your child is better able to communicate, reducing distractions so your child is better able to control his impulses and making expectations as clear and concrete as possible.

Adis enjoys going to movies and hockey games but can become easily agitated and upset while in the community. Some triggers for Adis were being in noisy, crowded environments. Some adaptations to the environment that were made included:

- having Adis enter crowded buildings a little before or a little after the big crowd.
- seating Adis at the end of an aisle and preferably close to a door.
- allowing Adis to bring his iPod with him to listen to if he felt he needed to relax.

Let's take a look at other environmental factors that you would consider to reduce challenging behaviour. Each factor may or may not be effective with individual children. It is important to get to know each child.

Remove distracting stimuli

Some children have difficulty coping when there are multiple objects within reach, and some find it difficult to concentrate or become over-stimulated when certain objects are nearby. For instance, some children find it very difficult to direct their attention towards a structured task when there is a television or computer in the immediate area.

Decrease sensory input

Remember the five senses: sight, sound, touch, smell and taste. Each child has different triggers:

- The lights may be too bright.
- The television may be too loud.
- What you ate for lunch may be lingering on your breath.

Any of these factors may serve as “the straw that broke the camel’s back” and trigger challenging behaviour.

Incorporate daily sensory experiences that are calming

Remember, what is calming for one child may or may not be calming for another.

- Drinking through a straw or sucking on a water bottle is calming for Chandra.
- Leo likes listening to classical music on his iPod.
- Johanne likes to rock in her rocking chair, but not for too long – this eventually makes her hyper.
- Basil finds squeezing a stress ball relaxing.
- Parker finds the stress ball has the opposite effect. He wants to rip the ball apart. However, fidgeting with pipe cleaners seems to have a calming effect.

Structure the child's time

Some children have difficulty with unstructured time. If a community activity involves a great deal of sitting or waiting, it may be helpful to take a quiet activity (e.g., a book) or “fidget toy” to occupy the child.

Use a timer

Timers can make task length/duration more concrete and achievable.

Sam has a hard time “waiting” for anything. His mother often says “just a minute” or “wait”, but it never seems to take a minute and, from his perspective, “waiting” seems to take hours. Using a timer makes the “waiting period” more concrete.

Schedule relaxation times

It is often helpful to schedule movement or exercise breaks before traditionally difficult times and/or times when a child will be expected to remain seated for an extended period of time.

**Note: It may be necessary to consult with an Occupational Therapist familiar with the sensory needs of the child you are working with to formulate a “sensory diet”. A sensory diet is an individualized set of therapeutic sensory activities that are typically implemented throughout the day to promote an optimal level of alertness and arousal.

Modify the physical arrangement of the room and/or body positioning

You may want to consider your body in relation to the child. If the child has poor impulse control, you may want to position yourself between the child and the object that they want, but shouldn't have. In the case of Noel, her mother positioned herself between the child and a potentially dangerous object:

Noel is an extremely active six-year-old girl. Going for walks in the community is one of her favourite activities. However, she often fails to look where she is going, darts away from her mother and has trouble staying on the sidewalk. Without close supervision, she walks into the street and is unaware of potential dangers. It is obvious that Noel should be closely supervised by an adult during community walks. Noel and her mother walked on park paths as practice. Another strategy is simple body positioning. Noel's mother made an effort to consistently walk on the side of the sidewalk that was closest to the street. That way, if Noel started moving towards the road, she bumped into her mother and readjusted her course by continuing to walk on the sidewalk.

Your Turn

Howie is a very impulsive 10-year-old boy with a developmental disability. Occasionally he will grab, pull and twist the clothing of others. He will also do the same to a person's hair – especially if it is long. Knowing this information, think about the type of adaptations you might make if you were Howie's parent:

- How would you wear your hair?
- Would you wear jewelry?
- How would you position your body if he needed help tying his shoe?
- What type of clothing would you wear?
- Would you wear a hat?
- What type of fidget toys do you think might appeal to Howie?

Provide a clear and predictable schedule

It is often helpful to provide a concrete schedule to make expectations clear and concrete. For instance, arriving home from school can sometimes be a chaotic time for families. For a child who has trouble communicating wants and needs and difficulties with changes in routine, this can be an extremely volatile. Having a simple visual schedule outlining expectations can help promote cooperative and desired behaviour. The example below is for a child who is much calmer after arriving home from school if she spends a few moments alone in her room, goes to the bathroom and then has snack time with her siblings.

Frequent reinforcement

Provide frequent access to items or activities that are reinforcing or calming to the child. For example, when he is out in the community Leo has the opportunity to listen to a few songs on his iPod if he becomes anxious or has to sit and wait.

Consider Your Behaviour

In addition to environmental adaptations, you can use proactive strategies that involve monitoring and changing our behaviour. How you interact with your child impacts the behaviour that your child displays. Here are a number of strategies that can be effective:

Provide choices within tasks

Keep in mind that many children with developmental disabilities have deficits in the area of communication. Imagine how frustrated you would be if you could not verbally make choices, request the things you want and reject the things you don't want. Children who have difficulty communicating can become easily frustrated by not having their choices or opinions heard.

Be careful not to offer a choice when there really isn't one. For example, what happens when you ask, "Do you want to have a bath?" and the child answers, "No"? Sometimes limited choices must be built into a specific activity (e.g., "It is time for bed. Do

you want your mom to read you a story or your dad?"). Other choices can be incorporated into a simple predictable routine (e.g., the choice of bedtime story, selecting which pajamas to wear).

Each child differs with respect to how many choices should be offered and how they should be presented. For example, Leo becomes overwhelmed if he is asked to make a choice when there are more than two alternatives. Furthermore, he needs visual supports to assist him in making a choice (e.g., a set of picture symbols or actual objects). If a choice is offered verbally, he always repeats the last option, even if it isn't what he wants.

Use task variation to alternate tasks that are demanding with those that are easier

It is often helpful to "sandwich" challenging tasks between preferred or relatively easy tasks. This helps to ensure that your child frequently experiences success and is intermittently reinforced. Also, it is important to end tasks before challenging behaviours are displayed, not after. This is why it's important to identify each child's "warning signs".

For example, Megan is good at matching objects that are the same and can complete simple inset puzzles. She just learned how to use a tripod grasp to hold a pencil and imitate straight lines and circles.

She has a great deal of difficulty using scissors and quickly becomes frustrated. Megan's mother discovered that she was much more tolerant of cutting if she was given an opportunity to engage in a preferred or familiar task before (e.g., matching, inset puzzles). Rather than expecting Megan to focus on cutting for several minutes, she presented the scissors a number of times, but only expected her to cut for a few seconds. Megan's mother made a conscious effort to end each cutting activity before she got frustrated.

Modify tasks to match the skills and interests of the child

It is important to assess each task to determine if it matches your child's current skill level. If it is too long or too difficult, your child may become frustrated and display challenging behaviour. Likewise, if a task is too easy, your child may become bored and display challenging behaviour.

Provide an appropriate level of prompting

Some children require hand over hand prompting during the initial stages of teaching. However, this type of prompting should be faded as quickly as possible. Rather than relying on physical prompting, break the task down or modify it so that your child can be as independent as possible. Provide only the amount of support that is necessary in order for your child to experience success.

Teach relaxation and calming techniques

Many children with complex disabilities have difficulty calming themselves down and reducing their level of arousal. Relaxation techniques can be taught using visual supports and imitation. Although different activities are calming for different children, progressive relaxation is often effective if it is taught in a concrete manner. Progressive relaxation involves tensing and relaxing groups of muscles and taking deep breaths.

Use "first-then" contingencies

When performing neutral or less-preferred tasks, it is often useful to remind the child of what preferred activity is coming up next ("First puzzle – then snack").

Vicky likes the school bus so much that she often refuses to get off of it when it arrives at her house. In the example below, a simple "first-then" schedule is used to remind Vicky that if she gets off the bus, she can earn a special treat.

Provide transition warnings

It is important to communicate when activities will be changing and when it is time to change locations. This can be accomplished using a timer or an alarm on a watch, using a visual schedule, marking events on a calendar, or simple verbal reminders (e.g., "five minutes until supper").

Provide clear expectations for behaviour

It is important to make expectations as clear and concrete as possible. For example, before going into a store with Neha, her mother reviews her rules (“No screaming. Keep hands to yourself.”).

Reward appropriate behaviour

It is important to reinforce your child for displaying adaptive, desirable behaviour to increase his motivation to display those behaviours in the future. Remember that the reward should be meaningful to your child.

Use visual supports

Children with Autism Spectrum Disorders tend to demonstrate relative strengths in concrete thinking, rote memory and visual-spatial relationships and difficulties in abstract thinking, communication and attention. In short, they tend to understand what they see better than what they hear. Keep in mind that one of the most effective ways to support and teach children with developmental disabilities is through the use of visual supports.



Think of your own life and what you do if there is something important that you need to remember – you write it down. On a daily basis, we use a variety of visual supports without even realizing it: Day timers, to-do lists, recipe books, phone lists, reminders scribbled on Post-it notes... the list is endless. Now imagine that you are a child who has a hard time understanding meanings and intentions, anticipating how one event affects another, comprehending unwritten rules and conventions, engaging in abstract reasoning and planning, and who has a short attention span. The world would be a confusing and sometimes scary place.

Children who have short attention spans and/or have difficulty processing verbal information can use the visuals for as long as they need to, while verbal instructions are “gone” as soon as they are given.

Anton likes the computer. However, when it does not work correctly, he tends to become agitated and often bangs the keyboard, screams and cries. His father posts a visual script beside the computer that he is encouraged to review each day before he uses the computer. The script outlines coping strategies for *What To Do When the Computer Doesn't Work Properly*.

Abby likes to play board games. Her mother has helped her work on turn-taking, but she still has a great deal of difficulty when she loses. Because of this, her siblings do not want to play with her. Therefore, prior to playing games a social script is reviewed with her. Over time, her mother faded the use of the script and Abby was eventually able to use the strategies independently.

Make task length concrete

It is important for children to understand not only what is expected of them, but “how much”. When using a visual schedule, it is often helpful to have the child remove the picture symbol of each activity after it is completed. For children who can read, you may ask them to cross off each task they complete. Similarly it might be helpful to encourage a child to place tasks in a “finished” box to make it clear when an activity is completed. Visual timers can also be used to help make longer tasks, or those without a clear end point, more concrete.

Noel is an active seven-year-old who has a hard time remaining seated for more than a few minutes. Her mother began using a timer when doing table top activities. When the timer rings, Noel knows that she can choose another activity. Initially, the timer was set for two minutes and, over time, it was gradually increased. Noel is now able to sit for up to 20 minutes.

Guidelines for Managing Behaviour

What can we do to increase the likelihood that the child cooperates with our request? The following may look familiar (it is covered in the Teaching Adaptive Behaviours Module):

- **Don't use a question when giving an instruction** – It may seem more polite to ask “Would you like to wash your hands before supper?” However, if there isn't a choice in the matter, you are better off being clear.
- **Get close to the child when giving an instruction** – Make sure you are close to your child when giving an instruction. Avoid giving instructions from great distances. If you have to shout, you are too far away. Also, be aware that we all have different personal space boundaries.

- **Use a neutral tone of voice; avoid yelling** – Children who are easily distracted or stimulated are not likely to respond to a booming tone of voice. It is also important to remember that children often learn through imitation and you often get what you give. That is, if you use a loud voice when giving an instruction, your child is more likely to respond with a loud voice.
- **Give children time to process requests** – Sometimes children need a minute (especially when instructions are given verbally) to process what is being asked of them. When giving instructions, allow your child ample time before repeating the instruction. If you jump in too early and repeat the instruction, you run the risk of interrupting their processing. However, if you wait too long, your child may become distracted with other aspects of their environment.

For example, Jill shouts “no” after almost every instruction. At first, her mother responded by getting into a debate with her, talking about manners and outlining possible consequences. This usually resulted in a tantrum. Over time, her mother learned that even though Jill said “no”, if she was left alone for a few moments she would usually follow through with the instruction.

- **Give only one instruction at a time** – Some children have difficulty following through on multiple-step requests and can be easily distracted. Provide instructions using language appropriate for your child. Some children are only able to follow one-step directions, while others can process and remember multi-step instructions.
- **Describe the behaviour you want** – Try to describe the behaviour you want to see (“hands on lap”), rather than the behaviour you don’t want to see (“no grabbing”). Noel would typically repeat the word “close”, but would not step back. Sometimes children do not know what to do as an alternative. For example, saying “no grabbing” can sometimes result in more “grabbing”. “Step back” was more effective than telling Noel what not to do.
- **Verbally praise compliance and cooperation** – The children who need verbal praise the most are often the ones who hear it the least. Keep in mind that it is often the child who is displaying challenging behaviour that has the attention of the adults in the room. If you do not attend to and reinforce positive, desirable behaviours, they tend to be displayed less frequently.

* Adapted from Rode, Ginger et al (1993) *The Tough Kid Book: Practical Classroom Management Strategies*. Longmont, CO: Sopris West Educational Services

Your Turn

Earlier, you learned that challenging behaviour can serve a number of functions for a child. Below are possible functions and possible proactive strategies that can be implemented to reduce the likelihood of the challenging behaviour occurring. Can you think of more?

1. Behaviour: Tim pokes others in the belly

Function: To gain attention

Proactive Strategy:

- Ignore behaviour
- Provide Tim with specific activities to play with others
- Neutrally redirect behaviour (e.g., “You can say ‘hi’ instead.”)
- Pay attention to desired behaviour (e.g., “Tim you are playing nicely all by yourself. What are you doing?”)
- Other: _____

2. Behaviour: Axel slaps his face when he is hungry

Function: To communicate a need or want

Proactive Strategy:

- Teach requesting
- Provide opportunities for choice
- Other: _____

3. Behaviour: Hunter forcefully presses his chin into the arms of the people sitting next to him

Function: To gain a sensory feedback

Proactive Strategy:

- Have others sit further away
- Provide fidget toys
- Provide regular movement breaks
- Other: _____

4. Behaviour: Bonnie runs out of the house when it is time for her bath

Function: To escape from an unpleasant situation

Proactive Strategy:

- Provide transition warnings
- Provide contingent reinforcement (e.g., first bath, then.....)
- Provide choices within the task
- Other: _____

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Unit 3

Developing a “Reactive” Plan

Reactive Plans

Behaviour management techniques include a wide range of approaches to reduce challenging behaviours and are typically part of a Behaviour Support Plan. A Behaviour Support Plan should be developed with the support and assistance of your Behavioural Aide, specific to the needs of your child.

The following are some of the commonly used “reactive” behaviour management techniques. Each of these techniques is covered in detail in the topics in this unit.

- Redirection
- Planned Ignoring/Extinction
- Response Cost
- Reprimands
- Corrective Responding: Restitution, Positive Practice, Appropriate Practice, and Overcorrection
- Negative practice
- Time Out

Remember, reactive behaviour management techniques should never be used in isolation. It is also important to identify and use proactive, preventative strategies, and also address skill deficits. Behaviour management techniques should be applied according to clear guidelines and in accordance with the

ethical standards of the professional involved. Some techniques may be approved in some settings and prohibited in others. Determining which technique to use and monitoring its use should be done in consultation with your Behavioural Aide and the appropriate professional.

Your Turn

What are some proactive strategies that you could use to help prevent challenging behaviours in your child? Now, think about a possible replacement behaviour (or skill) that could be taught to your child. The replacement behaviour should serve the same purpose as the challenging behaviour. Hint: think about why your child is displaying the behaviour. Determining proactive strategies and having a plan to teach replacement behaviours are important things to consider when thinking about using a “reactive” behavioural technique within a Behaviour Support Plan.

When making decisions regarding which techniques to use, you need to consider the function of the behaviour for the child or youth in consultation with your Behavioural Aide and a Psychologist or Behaviour Specialist/Consultant. Let's look at some of the commonly used reactive behaviour management techniques.

Least Restrictive Treatment

What is Least Restrictive Treatment?

Treatment approaches vary in how they are perceived by the child or youth. Some approaches may be perceived as positive (e.g., reinforcement) and some may be perceived as negative (e.g., time out). Treatment approaches also fall along a continuum from least to most restrictive, with the most restrictive approaches being those that are likely to be perceived as negative. Less restrictive treatment approaches may include reinforcement, modifying the environment, neutral

redirection, and other proactive strategies. More restrictive or negative approaches should never be used until it has been demonstrated that less intrusive (and more positive) techniques are ineffective and the child's behaviour continues to cause serious problems. Documentation (e.g., objective data collection) should be used to justify the use of more restrictive behavioural techniques.

Why is Least Restrictive Treatment important?

It is important to start with the least intrusive treatment to protect the safety, well-being and rights of your child. That is, one should strive to:

- prevent the possibility of psychological harm.
- prevent the loss of dignity.
- prevent violation of the child's or youth's rights.
- prevent injury to the child, youth or adult involved.

Redirection

What is Redirection?

With redirection, your child's attention is shifted from displaying a challenging behaviour to a more neutral or positive behaviour or activity. This can be done by directing your child to engage in a more appropriate behaviour or activity or to a more suitable environment.

- Directing your child to a more suitable environment (e.g., a child who is disruptive as he reads aloud is asked to take his book to the reading corner).
- Directing your child's attention to a more appropriate activity (e.g., pointing to an appropriate activity or placing it in front of the child).
- Giving your child a simple task to complete in order to create a distraction from the challenging behaviour (e.g., A child is directed to the bathroom to wash his hands before snack. On the way to the bathroom, he starts screaming and lies on the floor. His mother gives him a tissue to put into the garbage. The child takes the tissue into the bathroom and puts it into the garbage. His mother then points to the sink and encourages him to wash his hands.).

When redirection is used, there should not be any focus on the challenging behaviour. That is, the behaviour should not be addressed or commented on. Your child's attention should simply be directed to another activity or behaviour.

In redirecting your child's attention to a more appropriate behaviour or activity, you are teaching him a more appropriate

alternative. Essentially, you are attempting to replace an unwanted behaviour with a more acceptable and appropriate one.

Sometimes, visuals can be helpful in redirecting your child's attention (e.g., pointing to a picture of "puzzle" to focus your child's attention on the puzzle when he is picking his nose).

Examples

- Caleb is sitting at a table, colouring a picture with his father. He suddenly stops colouring and begins to scream while looking at his father. He gives him a new crayon and taps the picture, "Let's colour the bunny's ear". Caleb takes the crayon and begins colouring bunny's ear. His screaming subsides.
- Kelsey is flapping her hands in front of her eyes at the dinner table. Her mother picks up her fork and places it in her hand, pushes her bowl of pasta closer to her, and says "Eat noodles". Kelsey ceases flapping and starts to eat.

When to use redirection

Redirection can be used for a number of challenging behaviours, including:

- disruptive behaviours (e.g., screaming),
- socially inappropriate behaviours (e.g., nose picking, spitting),
- minor tantrums,
- self-stimulatory/stereotypic behaviours, and
- minor destructive behaviours (e.g., throwing toys).

The level of severity of the behaviour will help determine if this is an appropriate technique; however, consultation with your Behavioural Aide and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan.

Redirection is often effective for children who are on the verge of tantrum behaviour, as it refocuses their attention to something that is more productive and appropriate before they are in a full-blown tantrum.

When to avoid redirection

Severe behaviours such as major tantrums, self-injurious behaviours, and aggression may be difficult to redirect as it may be difficult to capture your child's attention, let alone redirect his attention from what is distressing/frustrating him. Other, more appropriate approaches should be explored for managing such behaviours.

Planned Ignoring/Extinction

What is Planned Ignoring/Extinction?

This refers to the deliberate withdrawal of attention during a brief period following the occurrence of the challenging behaviour. Basically, the reinforcement that maintains the challenging behaviour (i.e., attention) is withheld. Ignoring involves breaking eye contact, not making any comments on the

behaviour, and avoiding any indication of being annoyed or frustrated, as this would provide the attention your child is seeking.

Determining the reason why a youth is engaging in a particular behaviour will determine if planned ignoring is appropriate.

Food for Thought

Ask yourself the following question:

Is your youth engaging in the behaviour as an attention-seeking behaviour?

If you answered “yes”, then planned ignoring may be an appropriate strategy to employ for that particular behaviour. Also, it’s important to remember that both positive and negative attention can be reinforcing for some children and youth. Therefore, the negative attention gained by acting out can be very rewarding for the youth.

In some situations, you may see an increase in the challenging behaviour before the youth realizes that he will no longer receive attention from engaging in the behaviour. When you first use planned ignoring, he may initially try harder to get your attention until he understands that he will not receive the attention that he is attempting to get. This initial increase in behaviour may be an increase in frequency, intensity or duration. It may even involve a more challenging behaviour being displayed (e.g., if one particular behaviour doesn’t gain the attention that the youth is seeking, he may begin to engage in a different behaviour).

Planned ignoring can be extremely effective in decreasing certain behaviours (i.e., attention-seeking behaviours) on a long-term basis, especially when it is combined with structured learning opportunities designed to teach the youth more socially appropriate ways in which to get his needs met.

It is also important to remember that it is the target behaviour, not the youth, which is ignored. Therefore, the positive, socially appropriate behaviours that the youth displays should be attended to, commented on, and reinforced.

When to use planned ignoring

Planned ignoring is often effective for behaviours that are attention seeking in nature (e.g., those displayed in an attempt to gain the attention of an adult). This can be determined through a functional behavioural analysis which can be completed with the assistance of your Behavioural Aide.

Since the behaviours are being ignored, this strategy is typically only used for relatively minor behaviours (e.g., screaming, minor ag-

gression that does not harm others, swearing, whining) that do not compromise the safety or well-being of others.

The level of severity of the behaviour will help determine if this is an appropriate technique; however, consultation with your Behavioural Aide and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan.

Planned ignoring is only effective if:

- the youth is provided with attention and is reinforced for more positive and adaptive behaviours,
- the reinforcement can be controlled (e.g., the attention of others in the environment can be controlled),
- it is implemented consistently by all caregivers, and
- the youth is taught a more appropriate way of gaining attention.

When to avoid planned ignoring

Some behaviours cannot be ignored as they compromise the safety or well-being of others:

- Severe aggression or self-injurious behaviours
- Behaviours which have a disruptive effect on those around them (e.g., fighting)
- Destructive behaviours that result in significant property damage (e.g., vandalism)

This strategy is not appropriate for behaviours that are intrinsically reinforcing, such as masturbation and self-stimulatory behaviours.

Planned ignoring will not be effective when the reinforcement cannot be controlled (e.g., the reaction and attention of others in the environment, such as a sibling who reacts

to his brother screaming to get the parents' attention).

In some group situations, planned ignoring may not be appropriate. That is, others may perceive the behaviour as acceptable if it is ignored. Remember, the benefit of using this strategy should outweigh the drawbacks.

Response cost

What is it?

Response cost is the withdrawal of a specified portion of reinforcement immediately after a challenging behaviour is displayed.

Often, it is used in conjunction with a token economy, in which your child earns tokens for engaging in appropriate behaviours. The tokens can be traded in for preferred items or activities. When using response cost, your

child can earn tokens for positive behaviours and tokens can be taken away immediately following challenging behaviours.

It is imperative that your child knows the “rules” of the response cost; your child should know exactly what behaviour(s) will result in loss of reinforcement, what can be done to earn back the lost reinforcement (e.g.,

tokens), and when the next opportunity to earn the reinforcement will occur.

Response cost may also involve removing a reinforcement, and not just a token, immediately after a challenging behaviour (e.g., Markus earns time to play “Go Fish” after working hard on his math sheets. While

playing “Go Fish”, Markus becomes frustrated when he does not get any pairs and rips one of his cards. In response, his mother tells him that cards are finished and then directs Markus to resume his regular routine.)

Examples

- Taja is an eight-year-old child who engages in a number of challenging behaviours, including biting, screaming and climbing on the furniture. Her father uses a token economy in which Taja earns stickers for displaying appropriate behaviour and loses stickers for displaying any of her challenging behaviours. Her father outlines this expectation using a social story, so that Taja understands how she can earn stickers, when she will lose stickers, and how many stickers she needs to earn in order to earn a trip for ice cream.
- Devin is getting ready to go swimming. He has some difficulty pulling one of his boots on. He throws the boot and then bites his mother. His mother tells him that he is not going swimming and that he can go back to his desk to continue his worksheets.

When to use response cost

It is important that your child understand the concept a token economy and delayed reinforcement. It is also important that your child understand that, when a reinforcement is removed (e.g., losing the chance to go swimming when aggression is displayed while getting ready), it is related to his behaviour.

The level of severity of the behaviour will help determine if this is an appropriate

technique; however, consultation with your Behavioural Aide and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan. These techniques may be suitable for more ‘severe’ behaviours and must be used under direct supervision of a Clinical Supervisor.

When to avoid response cost

Children who do not understand the concept of a token economy will have a difficult time understanding how their behaviour relates to tokens being earned and lost. Further, children who do not understand how a consequence (e.g., such as reinforcement being removed) is related to their behaviour may

not benefit from response cost. Finally, children who do not understand cause and effect (e.g., children with FASD) will not understand either of these concepts.

Response cost should also be avoided when it is not possible to remove/add tokens immediately following specific behaviours.

Reprimands

What is it?

Reprimands are statements (e.g., “No hitting”) indicating that a specific behaviour is inappropriate.

A reprimand identifies the inappropriate (i.e., challenging) behaviour and indicates disapproval of the behaviour, but not disapproval of the child or youth.

When using a reprimand, you should be direct and firm but not scream or yell at your child. Remember, voice control is critical.

The effectiveness of a reprimand may be increased, in some cases, by pairing it with other behavioural approaches (e.g., time out).

Teaching more appropriate behaviours is very important so that your child or youth knows which behaviours are acceptable and which are not.

Examples

- Kieran is helping her father mix cookie dough in the kitchen. When he turns to get the eggs out of the fridge, Kieran climbs onto the counter to get closer to the mixing bowl. Kieran’s father issues a firm reprimand, “Get down. There is no climbing” and removes her from the counter. He reminds her that she needs to stay on her stool and that she can ask if she wants the bowl to be closer.
- Denny is watching TV when his younger sister enters the room and changes the channel. Denny pushes his sister. His mother responds immediately with “No pushing. You need to sit out” and directs Denny to sit on his “time-out cushion” on the other side of the room. Once his time-out period is over, Denny’s mother reminds him that, when he gets mad, he can count to 20 and then think of a way to solve his problem.

When to use reprimands

Children who are capable of understanding what is expected and capable of behaving in more appropriate ways may benefit from reprimands.

Reprimands are only effective when your child’s receptive communication allows her to fully comprehend what you are telling her. “No hitting” has a very different meaning if your child does not understand the meaning of the word “no”.

The level of severity of the behaviour will help determine if this is an appropriate technique; however, consultation with your Behavioural Aide and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan.

When to avoid reprimands

This approach will not be effective for behaviours that are displayed in an attempt to gain the attention of an adult (i.e., attention-seeking behaviours). If attention is maintaining a challenging behaviour, using a reprimand will only maintain, if not increase, the behaviour.

Time Out

Time out involves moving your child or youth away from potential sources of reinforcement. The use of time out should be paired with teaching strategies to increase your child or youth's ability to recognize when she is anxious or angry and to calm herself down. Also, it is important to remember that

time out will only be effective if "time in" (e.g., time in the original environment) is motivating/reinforcing for your child. Physical interventions may, for some children and youth, be necessary to safely transport them to a safe area or room.

There are two types of time out:

- Non-exclusionary (Contingent Observation)
- Exclusionary

Let's take a look at the different types of time out.

a) Time out: Non-exclusionary (Contingent Observation)

What is it?

The child or youth is removed from an activity or group of people upon the occurrence of a challenging behaviour. The child remains inside the same room, but in a different physical space, and can observe what is happening but not participate. Remember, time out will only be effective if "time in" (e.g., time in the original environment) is motivating and reinforcing for the child.

When using non-exclusionary time out, the adult should not give the child any unnecessary attention (e.g., verbal or non-verbal).

Time-out periods should be terminated when the child begins displaying appropriate behaviours or after a predetermined length of time. As a general rule, a child's time-out period may be one minute in length for every year of age (e.g., a four-year-old would sit out for four minutes). However, more or less time for the time-out period may be appropriate and should be determined by the clinician involved in the child's Behaviour Support Plan (e.g., a longer time-out period may prove to be more effective in modifying a particular child's behaviour). A clinician may also suggest

that the child's time-out period end once his behaviours subside (e.g., if a child is directed to a time-out area for engaging in tantrum and aggressive behaviour, he may be told to return to his activity once he calms down, if he tends to calm relatively quickly). Other children may require more time to ensure that they are completely calm, as some children appear

calm only to engage in further behaviours once directed back to an activity.

Often, at the conclusion of the time-out period, a simple request is made of the child (e.g., follow a simple direction), which helps to demonstrate if the child is calm enough to return to the activity or group.

Examples

- Noel is playing a board game with his parents and two older siblings. He picks up a card that reads “miss your turn”. Noel screams, throws his game piece and hits his sister, who is sitting closest to him. His mother immediately directs him to sit a short distance away from the rest of the family and they continue to play the game as he watches. After four minutes, his mother gets him to imitate three simple actions (e.g., clap hands, touch nose, put hands in lap) to determine his mood and level of cooperation. She then tells him that he can come back to the table and play the game. She also reminds him of his rules, which are outlined visually.
- Manesha is making a craft with a small group of peers. She has difficulty opening the cap on the glue and begins to scream. Her mother goes over to see why she is screaming. Manesha hits her mother as soon as she approaches her. Her mother directs Manesha to sit a short distance away on a chair. She watches as her peers continue making their crafts. When she appears to be calm, her mother asks Manesha to point to her eyes, elbow, and nose as a “calm test”. She then asks her to return to the table. When Manesha picks up her glue stick, her mother models how she can ask for help (e.g., she turns to a peer and says “open”). She gives the glue stick back to Manesha and provides prompting so that she asks her peer for help.

When to use time out: non-exclusionary

Non-exclusionary time out is most effective when used in the context of group activities or a structured activity from which your child can be removed.

Your child must perceive the environment from which she is being removed to be more reinforcing (e.g., enjoyable) than the time-out period.

This technique may be appropriate when the target behaviour does not result in harm to others (e.g., your child does not

continually target others when she is upset).

For more severe behaviours, including severe repetitive aggression, exclusionary time out may be more appropriate. The level of severity of the behaviour will help determine if this is an appropriate technique; however, your behavioural support team and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan.

When to avoid time out: non-exclusionary

This approach will be less effective if your child perceives the time-out period to be more reinforcing (e.g., enjoyable) than the activity from which she is being removed. Some children and youth display challenging behaviours in order to avoid their immediate environment or task (e.g., their behaviour is displayed in an attempt to escape their current situation). This can also be learned. Youth may begin to, or continue to, act out once they learn that it results in changing their current situation. For example, a youth is asked to sit out for kicking his brother during dinner. The youth dislikes sitting at the table during meal-times and prefers to carry his snacks around

with him throughout the day. He soon learns that kicking his brother gets him away from the dinner table and this behaviour actually begins to increase.

This approach may not be effective for children who are highly aggressive or destructive and are not able to control their actions (e.g., continue to engage in aggressive behaviours, like charging at others, once the time out has been implemented).

This approach would not be appropriate for behaviours which would continue to be displayed in any environment (e.g., self-injurious behaviours, masturbatory behaviours).

b) Time Out: Exclusionary

What is it?

Your child or youth is removed completely from the room to a specified area, such as the hallway outside of the room or a specific room. The youth is not able to observe or participate in the activity in which he was engaged prior to the behaviour. This form of time out is considered more restrictive than non-exclusionary time out since it involves the use of a separate space. An appropriate time-out area should be determined (e.g., safe, free of objects which can be thrown, large enough to comfortably move around). The time-out area may be the hallway right outside the room or another designated room.

This technique should always be considered a temporary measure with the goal being to re-integrate your youth into his regular environment.

Time-out periods should be brief (e.g., one to five minutes) and your youth should always be monitored while this approach is being used.

Often, at the conclusion of the time-out period, a simple request is made of the child (e.g., complete a simple neutral task) which helps to demonstrate if the youth is calm enough to return to the original activity.

Example

- Melody engages in severe aggression when she loses games. She is directed to the hallway when she is aggressive, just outside the living room where her family often plays games together. Her mother and father take turns directing her to time out so that she responds to both of them. During a time-out period, Melody is expected to sit in the hallway for five minutes and then complete a short task (e.g., putting 20 pennies into a small container with a hole in the lid). Once she has demonstrated to her mother (or father) that she is calm enough to complete this task, she returns to the living room and resumes the game with her family.

When to use time out: exclusionary

This approach would only be used when all other approaches have been exhausted. That is, when it has been shown that other techniques are not effective or not able to prevent harm to others (e.g., when the use of a non-exclusionary space results in others getting injured). Consultation with a trained professional is highly recommended.

This may sometimes be used in emergency situations where your child, youth or

others are at risk of being harmed.

The level of severity of the behaviour will help determine if this is an appropriate technique; however, consultation with your Behavioural Aide and their clinical judgment will ultimately determine an appropriate technique to use within a Behaviour Support Plan. These techniques may be suitable for more 'severe' behaviours and must be used under direct supervision of a Clinical Supervisor.

When to avoid time out: exclusionary

As with non-exclusionary time out, this approach tends to be less effective if your child perceives the time-out period to be more reinforcing (e.g., enjoyable) than the activity from which she is being removed. Some children and youth display challenging behaviours in order to get out of their immediate environment (e.g., their behaviour is displayed in an attempt to escape their current situation). This can also be learned. Youth may come to act

out once they learn that it results in changing their current situation.

This approach would not be appropriate for behaviours which would continue to be displayed in any environment (e.g., self-injurious behaviours, masturbatory behaviours).

General Guidelines

Reactive consequences should be:

1. Immediate and Consistent

The imposed consequence (e.g., behaviour management technique) should immediately follow the challenging behaviour. This helps to ensure that your child or youth makes the connection between her behaviour and the imposed consequence.

The consequence should be used after every instance of the target behaviour. Occasional use tends to be less effective than consistent use. Further, the same consequence or technique should be used by all caregivers in all environments. It is more difficult to reduce or extinguish behaviour if it is responded to differently by different people. This sends mixed messages to your child or youth.

Always follow through with the consequence. Never threaten a consequence that you are not able or willing to apply.

Deliver the consequence in a calm and direct way. Try to avoid showing emotion and do not scream or yell. Always maintain self-control when using behaviour management techniques.

The consequence should not be presented with reinforcement, as this weakens the effect of the consequence. Rather, it should be presented in such a manner that positive reinforcement is not paired with it (e.g., carrying a small child over to his time-out area may be interpreted as a hug by the child, which may be reinforcing for that child).

2. Logical and meaningful

Consequences should be logically connected to the challenging behaviour. If your child tears paper during a group craft, your child may have to sit out and not participate in craft that day. Having your child miss out on music group later in the afternoon does not make a lot of sense, as it is not connected to the behaviour.

The consequence should match the magnitude of the behaviour. Consequences should not be too lenient or too severe for the behaviour that is displayed. Using time out for a child who picks his nose is excessive.

3. The least restrictive alternative

Less restrictive approaches and techniques should always be used first. These need to be deemed ineffective, by thoroughly evaluating them, before more intrusive techniques are explored. Supervision from the ap-

propriate professional should be sought when more restrictive behaviour management (e.g., “reactive”) techniques are being contemplated.

Possible Pitfalls: How to Avoid Them

Potential Pitfall	How to Avoid
Behaviour Management Techniques do not teach appropriate or “correct” behaviour; they temporarily remove the challenging behaviours. They are a reaction to challenging behaviours; they do not teach what to do, only what not to do.	Within a Behaviour Support Plan, one should have a clearly defined plan to teach your child or youth adaptive skills or behaviours which serve the same purpose as the challenging behaviour. Multiple opportunities should be made to teach your child the adaptive skill (or behaviour), in addition to implementing proactive strategies to help reduce the likelihood of the behaviour occurring.
Behavioural change may be very slow, or absent, if there are inconsistencies in approaches. Further, if the behavioural approach is not available (e.g., the challenging behaviour occurs in a different environment that is not set up for a specific approach) there may be an increase in either frequency or duration of the behaviour over time.	All individuals involved with your child must be consistent in their “reactive” approaches. Otherwise, they run the risk of teaching your child that each person in his life has different rules. The challenging behaviour will not only continue to be displayed, but may even increase as your child tests each individual to see how they respond to him. Keep in mind intermittent reinforcement is more powerful and resistant to extinction than continuous reinforcement.
The technique can’t be used in all environments	Possible adaptations to the behavioural technique must be considered so that it can be used in a number of different environments. For example, if your child’s time out involves sitting on a mat in the living room when she is at home, you could modify this when at the doctor’s office (e.g., have the child sit in a quiet area on any other visual cue, such as your purse or a magazine found on the table).
The environment and people can be perceived as negative because of their association with the technique used in response to a challenging behaviour.	The adult implementing the technique should strive to maintain a calm and direct approach. Screaming and yelling should never be part of the delivery. “Time in” (e.g., the time that your child is not in time out) should be reinforcing. “Time in” may need to be modified to increase its reinforcing value if your child is no longer motivated to be in the environment.
Behaviour management techniques may have a negative impact on your child’s self-esteem. If corrective feedback is given to your child without any positive feedback or teaching (of appropriate skills and behaviours), self-esteem may be impacted.	Reinforcement, in addition to other positive proactive strategies, should be a large component of your child’s Behaviour Support Plan. This allows for many opportunities to offer your child positive feedback for displays of appropriate behaviours and also allows for teaching opportunities to further skill development. The positive feedback and positive teaching opportunities should outweigh the negative feedback from imposed consequences. Further, replacement behaviours, which serve the same purpose as the target behaviour, should always be taught within a Behaviour Support Plan.
Children and youth imitate behaviours and may use behavioural techniques on others.	You could teach the child about “jobs” (e.g., the parent’s and Aide’s job is to enforce the rules; this is not the child’s job). Further, if you treat children fairly and individualize each Behaviour Support Plan (e.g., the consequence matches the magnitude of the behaviour), then it is less likely to be a problem.

References and Resources:

Alberta Education. (2008). Supporting positive behaviour in Alberta schools: A classroom approach. Edmonton, AB: Author.

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Unit 4

Crisis Management

Intervening When Challenging Behaviours are Displayed

As discussed elsewhere in this unit, one of the primary goals of a Behaviour Support Plan is to decrease the likelihood that challenging behaviours are displayed. This is achieved by teaching your child or youth adaptive skills (ideally, that serve the same function as the challenging behaviour), and by identifying and implementing proactive strategies. Unfortunately, Behaviour Support Plans are often not effective immediately after they are implemented and often require revisions. Therefore, even when a well-thought out and comprehensive plan is in place, you should

expect your child or youth to display some incidents of challenging behaviour. Planning ahead tends to be the key to success.

When your child/youth displays behaviours that have the potential to cause harm to themselves or others and/or physical damage to the environment, it is important to discuss this with your Behavioural Aide and give some thought to how the reactive portion of the Behaviour Support Plan will be implemented.

Here are some things to consider:

- What can I do ahead of time to promote safety?
- What can I do while my child/youth is acting out to de-escalate the situation and promote safety?
- What can I do after the incident to promote safety?

These questions are covered in the next topics.

What Can I Do Ahead of Time to Promote Safety?

Think of it this way – hope for the best, but be prepared for the worst case scenario. Start by thinking about yourself. Are there things that you could do or change to decrease the likelihood of harm or destruction?

Dress/Appearance

In some situations, changing the way you dress may decrease the likelihood of certain behaviours being displayed. For instance, if you know that your child tends to pull hair when he is frustrated, it might be helpful to wear a hat or cap, or tie your hair back. Similarly, if your child or youth is prone to pinching, it might be helpful to wear more than one layer of clothing or long sleeves. Finally,

think of the activities you may be doing (e.g., chasing your child who is running away or assisting with a messy craft). It is important to select clothing and footwear that allows you to fulfill these responsibilities. In a crisis situation, quick action is necessary; taking the time to remove an expensive piece of jewelry or change your shoes may put yourself or others at risk.

Environment

Consider the different environments where your child/youth typically spends her time. This will likely include home, school and backyard, as well as a variety of community settings (e.g., swimming pool, recreation

centre, church). The next step is to think about your child/youth's behavioural challenges and how the environment could be modified to decrease the chance of injury or destruction.

Here are some examples:

- If your child tends to throw things, it might be helpful to place small, heavy objects out of reach.
- If your child tends to lash out towards other children when she is frustrated, you may want to modify seating arrangements, so that there are not any children within arm's reach.
- If your child is prone to running, arrange the setting so there are no clear runways.
- If your child tends to mouth/ingest small objects, you may want ensure that items that can fit in your child's mouth are kept in cupboards or containers that she is not able to open. This will help to ensure that such materials are only used when your child's activities are closely supervised.

- If your child tends to be destructive when she is distressed, survey the room for breakable items and, if possible, remove them until your child's coping skills improve. If this is not possible, give some thought to what activities/tasks tend to be frustrating for your child and make an effort to complete them in a "safe" room/location (i.e., one that does not have windows or breakable materials within reach).
- If your child tends to display aggression, it is a good idea to avoid seating arrangements where the child is positioned between you and the door. Similarly, if your child tends to hit or grab during certain activities, it might be possible to arrange the room so that you are sitting across the table and out of arm's reach.

Clarifying roles

When your child or youth is acting out, immediate intervention is often necessary. That is, there is often little or no time for discussions about "who" should be intervening and what the intervention should be. As

noted earlier, (link) the reactive portion of your child's Behaviour Support Plan should outline what to do in a step-by-step manner. To ensure that the plan is successful, it is important to clarify roles.

This may involve determining who will:

- take primary responsibility for the reactive plan (keep in mind it is usually beneficial to have only one person giving directions and talking to the acting out child),
- provide back up support (if necessary), and
- take action to ensure the safety of others in the environment (e.g., ask siblings or peers to leave the area, removing potentially dangerous objects from the immediate area).

Confidence

Another factor to consider is your level of confidence about implementing the reactive portion of the behaviour support plan and intervening when your child or youth is acting out. It is often helpful to talk to others on your support team and practise the suggested techniques with their supervision. Knowing

what to expect can help you to assess your comfort level. If you do not feel that you have the skills to handle the situation effectively, you may want to arrange for additional support from clinicians on your team.

What Can I Do While My Child/Youth is Acting Out to De-escalate the Situation and Promote Safety?

Match your intervention to the behaviour being displayed

Challenging behaviour can take many forms. In some cases, it involves physical acts such as hitting, kicking or throwing, while in other situations it may be limited to verbal acts (e.g., screaming, swearing, making threats, protesting). It is essential to select your intervention method based on the behaviour being

displayed. It makes no sense to use a physical intervention, such as restraint, if your child is yelling and swearing. Similarly, verbal interventions will likely be ineffective if your child is attempting to hit or attack you.

Food for Thought

It makes no sense to use a fire extinguisher to put out a candle, just as it makes no sense to use an eye dropper to put out a campfire. Think of situations you have observed, or been a part of, where the intervention seemed to be inconsistent with behaviour displayed.

What was the end result?

You may have noticed that there are risks associated with both under- and over-reacting. Over-reacting may escalate the behaviour, while under-reacting may increase the risk of injury.

Limit the number of people involved in the intervention

Try to determine the minimum number of people required to ensure the safety of all involved. In some cases, the presence of additional people may inadvertently lead to an escalation of behaviour.

Communication

Children and youth with developmental disabilities often have difficulty understanding what is communicated to them. When a child is extremely upset, his ability to process information is often further compromised. Therefore, it is critical to reduce your language level, reduce the number of words you use, and/or use an alternate mode, such as gestures or picture symbols, to communicate with the acting out child.

Remember, communication is more than the words we say. It is also how we say them, tone, volume and inflection. A statement can have dramatically different meanings depending on how it is delivered. For instance, a simple question such as, “Do you need help?” takes on different meanings depending on the volume, tone and inflection of the speaker. That is, it can shift from being a

supportive gesture to one that implies disapproval or disappointment.

Depending on the situation, you may experience different emotional reactions, such as fear or frustration. Although this is normal and to be expected, it is important to try to project a sense of calm to your child. If you hear emotion in your voice, make an effort to slow your breathing. In some cases, your child or youth may respond by doing the same. If you feel that your voice is going to sound overly “emotional”, it may be better to rely on gestures, picture symbols or have another adult take responsibility for the situation.

Keep in mind that hearing an emotional voice may be distressing to your child and has the potential to escalate the situation.

Non-verbal communication

It is important to consider the role of eye contact and body posture in communication. At times, direct eye contact can be perceived as quite threatening. For this reason, it is often beneficial to closely monitor your child, but avoid making direct eye contact with him or her. That is, unless they are attempting to seek out information or guidance from you. Similarly, there a number of gestures that can be perceived as threatening. These

include: standing over someone, waving your finger or hands, crossing your arms in front of you, frowning and/or stepping directly in front of someone. Therefore, it is important to try to maintain a relaxed stance with your arms/hands visible. Such a position appears less threatening and also puts you in a “ready position” in case you need to move quickly to address a safety issue.

Personal space

The term “personal space” refers to the area surrounding our body that we consider an extension of our self. People generally feel uncomfortable, or even threatened, when others violate our personal space without permis-

sion. The same holds true for children and youth with developmental disabilities. Some children and youth with disabling conditions, such as Autism Spectrum Disorders, tend to have larger personal space boundaries than

their typically developing peers. Also, when someone is agitated or distressed, their personal space requirements tend to increase. This is a critical point to keep in mind when you are attempting to intervene. Ask yourself

the following: when he is calm, what are his personal space requirements? When your child is distressed, it is important to give him increased space.

Putting Everything into Action: Your Crisis Management Plan

As mentioned earlier, Behaviour Support Plans often require days or weeks to impact a child or youth's behaviour. In the meantime, you need to be prepared to implement the reactive portion of the plan in a manner which promotes safety. In this unit, we presented several issues that should be considered (e.g., your dress, the environment, communication style) when you are working with your child or youth who displays behaviours that have the potential to cause harm or damage.

In conjunction with your team, it is often helpful to write up a summary or individualized Crisis Management Plan to encourage everyone to handle potentially dangerous situations in a consistent manner. Crisis Management Plans often: outline ways to

modify the environment to promote safety, clarify the role(s) that different people will play when the plan is implemented (e.g., who will do the talking), indicate what should be said to your child/youth and how the information should be delivered (e.g., verbally or using visual supports), outline when, and under what conditions, physical intervention should be used and provide helpful hints for the parent or Aide implementing the plan (e.g., what to wear, how to stand, etc.).

In conjunction with your Behavioural Aide, their agency and/or clinical supervisor will work with you to identify strategies to deal with behavioural outbursts and, ultimately, to develop a Crisis Management Plan.

Physical Interventions

A caution

Physical interventions are reactive responses or crisis management techniques. Make no mistake, they are not implemented to change or reduce the frequency of a specific behaviour. They are intended to protect, not punish. Physical interventions are implemented in a crisis situation, when a child or youth has lost control and poses a risk to themselves or others. The key to success is to avoid challenging behaviours by teaching adaptive skills and using proactive strategies.

If your child or youth's behaviour has escalated to the point that you feel interventions are necessary to maintain safety, professional help/support should be sought. It may be possible to contract a private Psychologist or seek consultation from one working within the health or education systems. Your Family Support for Children with Disabilities Worker may be able to provide support and advice if such consultation becomes necessary.

What Can I Do After the Incident to Promote Safety?

Debrief

Thoughtful reflection is essential to program monitoring. Debriefing can occur at an individual level (taking time to learn from/reflect on the incident) or team level (discussing the incident in detail with others involved in your child or youth's life). Following each "critical incident", take time to consider:

- Did the intervention "match" the behaviour displayed?
- How could a similar incident be avoided in the future?
- Did other family members play a role in the incident?
- Would a change of time, location or organizational strategy have changed the outcome?
- If a similar incident did occur, is there a less restrictive or more effective way to handle it?

Self-care

Some incidents may be emotionally traumatic to the people involved. While different people have different thresholds for stress and different coping styles, it is important to remember that self-care is critical for everyone. Team discussions may be sufficient in some situations and professional support/counseling may be necessary in others.

Food for Thought

Take a minute to think about your support networks. Who are the people or systems you rely on in time of stress? What activities do you engage in to alleviate/manage stress? Do you feel your supports and efforts are enough? If the answer is no, you may want to talk to other parents or your FSCD worker to improve your stress management and self-care plan.

References and Resources:

Alberta Education. (2008). Supporting positive behaviour in Alberta Schools: An intensive individualized approach. Edmonton, AB: Author.

Child Welfare League of America. (2002). CWLA best practice guideline. Washington, DC: Author.

Unit 5

The Key Elements of a Behaviour Plan

The Importance of Behaviour Support Plans

The purpose of a Behaviour Support Plan is: prevention, accommodation, and teaching appropriate replacement behaviour or skills. When behaviour becomes a danger to your child or others, or if it interferes with your child's ability to learn or participate in activities, then it is recommended that a "plan" be developed, put in writing and implemented.

Behaviour problems are often the primary concern to families of children with developmental disabilities. Problem behaviours can be disruptive and stressful to the family, interfere with learning new skills, and impact meaningful inclusion in the community. Many families find that traditional discipline methods – those that worked when they were children, and those that seem to work with typically developing children – don't seem to be as effective with children and youth with complex disabilities.

Some challenging behaviours are a direct result of a skill deficit. You also learned that children and youth with complex needs

often require intensive and individualized strategies to learn new skills [link to teaching adaptive behaviour]. Therefore, behaviour management involves much more than simply having a procedure to follow when a challenging behaviour is displayed. Behaviour Support Plans outline how to avoid challenging behaviours by teaching new skills and using proactive strategies, as well as what to do when such behaviours are displayed.

Behaviour Support Plans should be developed through a collaborative process involving your family, your Behavioural Aide, other professionals (as required) and the significant people in your child's life. Such a plan is especially critical when children display behaviours that have the potential to cause harm to themselves or others (e.g., repeated aggressive, destructive or self-injurious behaviour). In such cases, it is recommended that the plan be put in writing as quickly as possible and evaluated on a regular basis. Later in this unit, we will go into greater detail about what should

go into a Behaviour Support Plan and provide examples and a written template.

Behaviour Support Plans are designed to implement strategies in a consistent manner across all of the key people in your child's life and across environments. For example, if it is decided that planned ignoring of a behaviour, such as screaming, is the most appropriate intervention for your child, then it is important that all key people in your child's life are following through in a consistent manner.

When addressing challenging behaviours, it is important to remember that one size does not fit all. Behaviour Support Plans should be individualized and based on the individual strengths and areas of need of your child, as well as the apparent function of the challenging behaviour. Plans should always reflect an understanding of the characteristics of your child's complex disability.

A Behaviour Support Plan should include:

- key understandings/theories about your child's behaviour,
- conditions or antecedents that are most likely to trigger the behaviour and the proactive strategies that can be employed to avoid it,
- warning signs that your child is experiencing difficulty,
- a plan for diffusing the situation,
- positive supports to help teach your child adaptive skills, and
- a reactive plan, which may include strategies for crisis management.

Key Elements of a Behaviour Support Plan

The theoretical framework of positive behavioural supports should be used when developing Behaviour Management Plans. This process begins with identifying your child's strengths and areas of need, the conditions that trigger and maintain challenging behaviour, and the conditions that trigger desired behaviours.

Key elements of a Behaviour Support Plan:

1. An understanding of the function of your child's behaviour and contributing factors.
2. Positive behavioural supports, including proactive strategies (e.g., adapting the environment or changing how we interact with your child to reduce the likelihood that the challenging behaviour is displayed) and a plan to teach specific skills in order to increase the frequency of more desired behaviours or replacement skills.
3. The use of reinforcement strategies to motivate your child to display adaptive behaviour and/or refrain from displaying challenging behaviours.
4. A procedure or reactive plan to employ when proactive strategies have been used, but the targeted behaviour still occurs.
5. A description of how the plan will be monitored and evaluated.

Developing a Behaviour Support Plan

Remember, the most important factor in developing a Behaviour Support Plan is to identify the function of the challenging behaviour. If you can think of one word or phrase that could replace your child's behaviour, you would be well on your way to finding an alternative behaviour that might replace the challenging behaviour.

Once you have collected information, understand the function of the challenging behaviour, know what triggers the behaviour and what reinforces the behaviour, it is time to think about a plan for intervention. The Behaviour Support Plan needs to include the following:

- interventions to avoid having the behaviour occur in the first place,
- what to do when the behaviour occurs, and
- a plan to teach a replacement behaviour.

Keep in mind that all of the components of your Behaviour Support Plan have to relate to the function of the behaviour.

When talking about replacing challenging behaviours, you will need to assess your child's current skills. Here are some situations you might encounter:

Your child does not have the skill

- If this is the case, break the skill down into teachable units, and teach steps (e.g., through direct instruction) and then ensure that skills are generalized (e.g., through rehearsal and feedback within routine activities and whenever the need for the skill arises)

Your child demonstrates the skill but does not use it functionally

- If this is the case, analyze the barriers to your child using the skill and teach when and how to use (e.g., through direct instruction) and then ensure that skills are generalized (e.g., through rehearsal and feedback within routine activities and whenever the need for the skill arises)

Your child has the skill but chooses not to use it

- If this is the case, identify conditions that relate to use of the skill (i.e., modify antecedent and consequence circumstances to increase the child's motivation to display the skill)

Involving the entire team

When developing a Behaviour Support Plan, it is vital to work with your Behavioural Aide and treatment team.

Behaviour Support Plan Considerations

When talking about replacing challenging behaviours, you will need to assess your child's current skills. Here are some situations you might encounter:

- **Your child does not have the skill**

If this is the case, break the skill down into teachable units, and teach steps (e.g., through direct instruction) and then ensure that skills are generalized (e.g., through rehearsal and feedback within routine activities and whenever the need for the skill arises)

- **Your child demonstrates the skill but does not use it functionally**

If this is the case, analyze the barriers to your child using the skill and teach when and how to use (e.g., through direct instruction) and then ensure that skills are generalized (e.g., through rehearsal and feedback within routine activities and whenever the need for the skill arises)

- **Your child has the skill but chooses not to use it**

If this is the case, identify conditions that relate to use of the skill (i.e., modify antecedent and consequence circumstances to increase the child's motivation to display the skill)

Example of a Behaviour Support Plan

Chynna

Chynna is 8 years old and has a developmental disability. She loves colouring books. Although she doesn't colour in them, she really likes to look at the pictures and flip through the pages. Chynna can verbally request a limited number of familiar, preferred objects such as "book" or "banana" using single words. She often displays tantrum behaviours when her parents say "no" to her. She can become upset quickly and seemingly without warning. When this occurs, she tends to scream and bite the collar on her shirt. If others are close to her at this time, she will attempt to scratch or bite them. Chynna's parents don't know what to do. They would like to work on expanding her vocabulary or work on toilet training, but Chynna's behaviour seems to interfere with learning.

The following is a Behaviour Support Plan that was developed for Chynna:

Name: Chynna - 8 yrs old

Objective: To reduce aggressive behaviour and maintain a healthy, safe environment for all parties.

Rationale: Chynna, on occasion, will display aggressive behaviours (e.g., hitting, biting or scratching those in close proximity to her).

Key Understandings:

- Chynna has difficulty coping with change.
- Chynna has difficulty with loud noises or when in distracting environments.
- Chynna tends to become frustrated with complex verbal instructions.

Plan:

Be aware of antecedent events:

- Chynna most often displays aggressive behaviour when:
 - arriving home from school,
 - there is a great deal of noise or distraction around her, and/or
 - she is denied a request (such as a request for snack food).

Be aware of warning signs (escalating behaviour):

- Chynna often displays the following when she is distressed:
 - she starts to rock and whine,
 - she drops to the floor, and/or
 - she begins to bite her shirt collar.

These behaviours should be considered communicative in nature and indicate that Chynna is having difficulty.

Immediate measures (list plans to diffuse the situation)

- Use a picture schedule to describe upcoming changes in routine.
- Avoid using a loud voice when speaking to Chynna.
- If denying Chynna a request, let her know when she may receive the item she is asking for (e.g., “Cookies after supper”).
- Only one person should be speaking to Chynna if she is displaying warning sign behaviour.
- Maintain a safe distance between you and Chynna if she is displaying warning sign behaviour.
- Make sure instructions and requests are short and allow time for processing.

Implement positive behaviour supports (proactive strategies and a plan to teach appropriate/alternative behaviour).

- Intermittently direct Chynna to her beanbag chair in her room and/or drink from a water bottle as these activities appear to have a calming effect on her.
- When Chynna first arrives home from school, direct her to a less distracting area first for a few minutes (e.g., her room to look at a book).

- Teach Chynna to use the words “too noisy” in conjunction with “too noisy” picture symbols to request an environment change.
- Provide frequent opportunities for choices in her routine to give her a sense of control.
- When denying a request, use a “first-then” contingency where possible (i.e., inform her when she can have the desired item). Also, try to incorporate picture symbols or a timer to make expectations concrete. For example, first you need to hang your coat up and then you may have a drink.
- Throughout the day, practice a calming routine with Chynna (e.g., taking deep breaths and counting to five).

Help peers/siblings learn to:

- Encourage Chynna’s brothers and sisters to give her space after school and to use their “indoor voices”.

Reactive Plan:

In spite of positive behavioural supports, if aggressive behaviours are displayed, the following plan should be implemented (i.e., a procedure for dealing with escalating behaviour that includes steps and responses for each level of escalation).

- If Chynna scratches, hits or bites, say “hands down”.
- Direct her to sit down in the immediate environment (e.g., a nearby chair).
- Use a point prompt to indicate where you would like her to sit.
- Move at least four feet away from her.
- Avoid making eye contact with her at this time.
- If Chynna is screaming or biting her shirt, do not speak to her or comment on her behaviour, although you may provide her with a toy she likes to chew on.
- When she shows signs of calming (e.g., she is quieter and is chewing less), intermittently provide her with model prompts from her calming routine, such as taking deep breaths).

- If she imitates the modeled calming behaviour and sits for 30 seconds without screaming, crying or biting her shirt, she should be neutrally directed to her usually scheduled activities.

Team members’ signatures:

Date: _____

Review date: _____

Here is a template you can use to develop your own Behaviour Support Plans (Adapted from Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Author).

Behaviour Support Plan

OBJECTIVE: To ensure that caregivers and Aides working with _____ are aware of behaviour support procedures in place to maintain a healthy environment for all parties.

RATIONALE: _____, on occasion, will

KEY UNDERSTANDINGS ABOUT

PLAN:

1. _____'s caregivers will read and sign this plan.
2. **BE AWARE OF ANTECEDENT EVENTS.** This behaviour is most likely to occur when:
 - A)
 - B)
 - C)
 - D)
3. **BE AWARE OF WARNING SIGNS** (escalating behaviours).
 - A)
 - B)
 - C)
 - D)

THESE BEHAVIOURS ARE COMMUNICATIVE IN NATURE AND INDICATE THAT _____ IS HAVING DIFFICULTY AND MAY ESCALATE.

IMMEDIATE MEASURES WILL INCLUDE: (List plans to diffuse the situation)

- A)
- B)
- C)
- D)

IMPLEMENT POSITIVE BEHAVIOUR SUPPORTS: (Describe proactive strategies to use consistently to support the student and that will increase his/her ability to communicate his/her wants and needs, and that will teach alternative, more acceptable responses to frustration.)

- A)
- B)
- C)
- D)
- E)
- F)
- G)

ASSIST PEERS/SIBLINGS LEARN TO:

- A)
- B)
- C)

ALL CAREGIVERS/AIDES WILL: (Include any other measures that the staff will need to take, and include a referral to the IPP).

- A)
- B)
- C)
- D)

REACTIVE PLAN: (In spite of proactive strategies, if aggressive or unsafe behaviour occurs, the following plan is in place: List a plan for dealing with escalating behaviour that includes steps and staff response for each level of escalation).

- A)
- B)
- C)
- D)

I have read this plan and am aware of support procedures to be followed when working with _____.

Note: A copy of this plan should be retained by all caregivers/Aides.

Signed: (Have all team members, including parents or guardians, sign the plan.

Date: (date plan was signed) _____

Date to review this plan: (Date that the team has agreed to meet): _____

References and Resources:

Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Author.

Alberta Education. (2008). Supporting positive behaviour in Alberta schools: An intensive individualized approach. Edmonton, AB: Author.

Horner, Robert H. and George Sugai. Developing Positive Behavioural Management Systems for Students with Challenging Behaviours. (Reston, VA: Council for Children with Behavioural Disorders, a division of The Council for Exceptional Children, 1999) pp. 15-23

Martin, G. & Pear, J. (2006). Behaviour modification: What is it and how to do it (8th ed.). Upper Saddle River, NJ: Prentice Hall.

Special Education Council of the Alberta Teachers' Association (2007). BOATS: Behaviour Observation Assessment Teaching Strategies (2nd Edition). Edmonton, AB:

Unit 6

Evaluating Behaviour Support

Data Collection

In the Teaching Adaptive Behaviours Module, we learned about the importance of data collection. We learned that data makes it possible for us to track progress and make decisions about the effectiveness of our teaching methods. Data collection is also critical when we are attempting to reduce/eliminate challenging behaviours. By collecting and analyzing data, we can make objective decisions about the effectiveness of a specific intervention or Behaviour Support Plan. This is accomplished by comparing baseline data, data collected before the intervention or support plan is put into action, to data collected

after the support plan is implemented.

As you may recall, there are many different types of data collection systems. The different systems are described in detail in the Teaching Adaptive Behaviours Module (Unit 4 – Evaluating Effectiveness, Topic 2 – Different Types of Data Collection Systems).

It is often helpful to think about the “goal” of the Behaviour Support Plan when trying to identify which type of data collection system would be most useful. This chart outlines common goals and data collection systems.

Goal of Behaviour Support Plan	Most Appropriate Type of Data to Collect
To reduce the number of times a challenging behaviour is displayed	Frequency data
To reduce the length of time it takes for a child or youth to calm down	Duration data
To teach the child or youth to use strategies to manage challenging behaviour(s) (e.g., calming strategies)	Level of independence data

The topics that follow provide examples to show you how different data collection systems could be used to evaluate the effectiveness of a Behaviour Support Plan.

Frequency Data

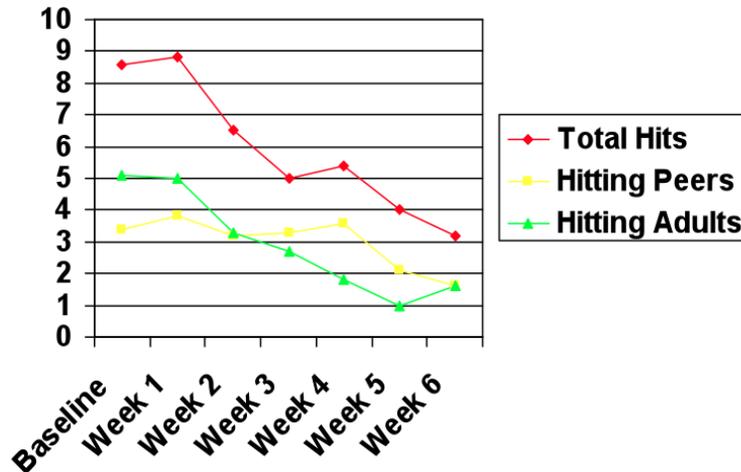
Fatima frequently hits others when she is frustrated. A Behaviour Support Plan was developed in the hopes of reducing this behaviour. Fatima's Aide started out by collecting baseline data to determine the frequency of hitting before the Behaviour Support Plan was started. Baseline data was collected over the course of one week. She used the following data sheet:

Date	# of times Fatima hit or attempted to hit a peer	# of times Fatima hit or attempted to hit an adult	Total
March 2	II	IIII I	8
March 3	III	IIII	8
March 4	III	IIII	8
March 5	IIII	IIII	9
March 6	IIII	IIII	8
March 7	III	IIII	8
March 8	IIII	IIII I	11
Totals	24	36	60

Once the baseline period was over, the Aide analyzed the data by calculating daily averages for each of the behaviours. She found that Fatima displayed an average of:

- 60 incidents over 7 days or an average of 8.6 incidents of hitting per day
- 24 incidents over 7 days or an average of 3.4 incidents of hitting peers per day
- 36 incidents over 7 days or an average of 5.1 incidents of hitting adults per day

Fatima's Behaviour Support Plan was implemented by her Aide and parents following the baseline period. To determine if the plan was effective, data was recorded on a daily basis. The Aide used the same data sheet that she developed to collect baseline data. At the end of each week, the Aide calculated daily averages and plotted the numbers on a graph.



The goal of Fatima's program was to reduce the frequency of hitting. If you look at the graph of her data, both of the targeted behaviours, hitting peers and hitting adults, decreased over the six weeks the Behaviour Support Plan was run. In this case, the plan appears to be effective. Therefore, the Aide would likely decide to continue running it until hitting was eliminated or reduced to a level that is appropriate for Fatima's developmental level.

Duration Data

William is four-year-old boy with an Autism Spectrum Disorder. He tends to become very distressed when unexpected events occur. For instance, he displayed tantrum behaviours (e.g., crying, dropping to the ground) for almost an hour when his preschool teacher introduced new play centres into the room. A Behaviour Support Plan was developed to teach William to use calming strategies to reduce the length of his tantrums.

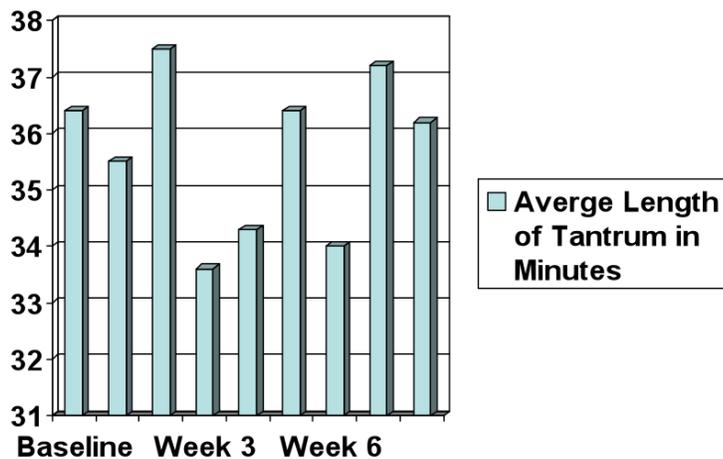
William's Aide started off by collecting baseline data to determine the average length of tantrums. He decided to record the length of 10 tantrums using the following data sheet:

	1	2	3	4	5	6	7	8	9	10	Total
Length of tantrum (in minutes)	42	36	51	40	27	48	22	39	26	33	364

Once the baseline period was over, William's Aide calculated the average length of tantrums.

- 10 incidents totaling 364 minutes or an average of 36.4 minutes per tantrum

At this point, the Behaviour Support Plan was put into action. To determine if it was effective, the Aide asked all of the people involved in William's life (e.g., parents, preschool teacher, respite worker) to continue to record the length of each tantrum. At the end of each week, the Aide calculated the average length of William's tantrums.



The goal of William's Behaviour Support Plan was to reduce the length or duration of tantrums. When you look at the graph, you see that tantrum length at the end of the six-week and tantrum length during the baseline period are quite similar. In this case, the Aide would likely conclude that the intervention is not effective and the plan would likely be modified.

Level of Independence Data

Rob is a teen with Asperger’s Syndrome. He tends to become agitated and aggressive when he hears screaming or other loud noises. His Aide developed a social script to encourage Rob to cover his ears, go for a break, or take deep breaths when he hears a loud noise. The Aide noticed that although Rob was able to follow the script, he generally needed prompting to use it.

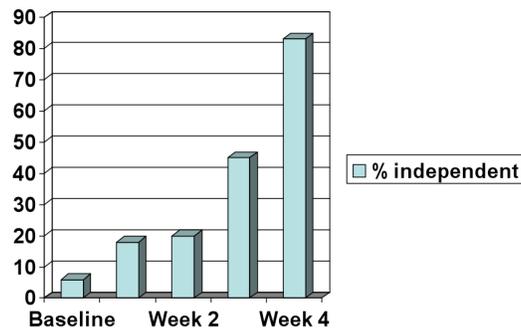
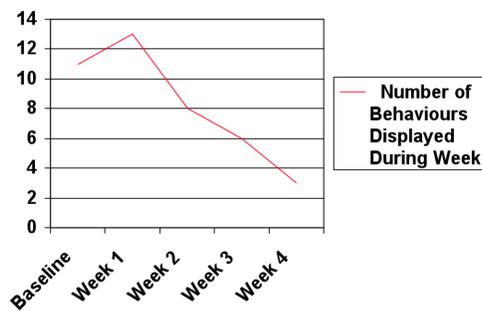
The Aide collected baseline data to determine the level of prompting generally required for Rob to access and use his script. Also, given that the ultimate goal of Rob’s Behaviour Support Plan was to reduce the frequency of agitated and/or aggressive incidents, the Aide also collected frequency data during the baseline period. Here is the data sheet she used and the data collected during the one-week baseline period.

Date Agitated/Aggressive Behaviour Displayed	Level of prompting required for Rob to access and use his “Loud Noises” social story
May 4	partial physical prompt
May 4	model prompt
May 4	partial physical prompt
May 5	model prompt
May 5	model prompt
May 6	partial physical prompt
May 6	model prompt
May 6	partial physical prompt
May 7	model prompt
May 7	model prompt
May 8	verbal prompt
May 8	verbal prompt
May 9	verbal prompt
May 9	Independent
May 10	model prompt
May 10	verbal prompt

The data was summarized by calculating the number of aggressive/agitated behaviours displayed during the week, as well as the prompting Rob to access and use his social story.

- Number of aggressive/agitated behaviours displayed during the week = 16 behaviours over 7 days = average of 2.20 behaviours per day
- Prompting required:
 - partial physical prompting was required 4/16 or 25% of the time
 - model prompting was required 7/16 or 44% of the time
 - verbal prompting was required 4/16 or 25% of the time
 - independent (no prompting required) 1/16 or 6% of the time

To monitor the effectiveness of the Behaviour Support Plan, Rob's Aide asked everyone to continue to record data after the Behaviour Support Plan was implemented. This allowed her to graph the number of agitated/aggressive behaviours displayed per week and the percentage of time Rob independently accessed his social story.



The Behaviour Support Plan was introduced to reduce the frequency of Rob's agitated/aggressive behaviours and to increase his ability to access and use his social story in an independent manner. As such, there are two graphs to consider. The first graph clearly demonstrates that agitated and/or aggressive incidents reduced after the Behaviour Support Plan was implemented, while the second graph shows that Rob's level of independence increased over the four weeks the plan was implemented. In this situation, the Aide would likely conclude that the program is effective and continue implementing it until agitation and aggression were no longer an issue.

Evaluating Effectiveness

As the previous examples demonstrate, decisions regarding the effectiveness of a Behaviour Support Plan should be based on objective data. Although your opinion is an important source of information, there is less opportunity for bias when decisions are data based.

To determine if a program is effective, it is important to consider what you hoped the program would achieve. As noted earlier in this unit, it is important to remind yourself of the ultimate goal of the program.

When assessing the effectiveness of a Behaviour Support Plan, there are several factors to consider:

Has the plan been in place long enough for results to be observed?

In some cases, it may take a few weeks for the child or youth to respond to the intervention. It is important to resist the urge to abandon ship (and your support plan) after only a few days. Keep in mind that some behaviours may actually increase in frequency when a Behaviour Support Plan is initially introduced. For instance, attention-seeking behaviours are often displayed more frequently when planned ignoring is initially introduced. Think about it from the child's perspective – “This behaviour brought me attention in the past... it is not bringing me attention right now, so I guess I better dial it up a notch!”

Is everyone implementing the support plan in the same way?

Consistency is critical. If one person is inadvertently reinforcing a challenging behaviour or failing to follow through when challenging behaviour is displayed, it will likely influence the overall effectiveness of the intervention. For this reason it is important to ensure that everyone understands and agrees with the Behaviour Support Plan before attempting to implement it.

Is the data accurate?

In some situations, the recorded data may not accurately represent what is actually going on. If people fail to record data, it may appear that a behaviour is being displayed less often than it actually is. This could lead one to conclude that a plan is effective when, in fact, it is not. If data is recorded inconsistently, it is very difficult to draw conclusions about the effectiveness of an intervention.

One way to increase the likelihood of accurate data is to define behaviours in a precise, concrete manner. Make it clear to people what you want them to record. For example, do you want them to record each and every act of aggression (e.g., each hit or kick) or do you want them to track episodes of aggression that might involve several acts?

What was going on in the child's life during the data collection period?

Specific events (e.g., birth of a sibling, family vacation), transitions (e.g., changing schools, moving to a new house) and/or medical/health issues (e.g., illness, medication changes, menstruation) may influence behaviour. These factors should be considered when you evaluate data and draw conclusions about a Behaviour Support Plan. For instance, a decline in challenging behaviours may be a result of illness, rather than the Behaviour Support Plan.

Revising Your Plan

In some situations, you may find that:

- a Behaviour Support Plan has been in place for a significant length of time,
- everyone is implementing it in the same way,
- accurate data is being recorded, and
- there does not appear to be anything notable going on in the child's life that would impact behaviour.

Yet, the plan does not appear to be effective. This generally means that it is “back to the drawing board” to rethink and revise your Behaviour Support Plan.

There are a number of ways to approach this task:

Review the existing data or collect new data to determine the underlying function of the challenging behaviour. It is possible that the Behaviour Support Plan is not effective because your initial theory about “why” the child is displaying the behaviour was incorrect. For instance, planned ignoring tends to be effective if a behaviour is displayed to gain attention. However, it tends to be much less effective if the child is displaying the behaviour to avoid or postpone a task.

Look at the reinforcement(s) being used. Are they “powerful” enough and provided often enough to motivate the child to display adaptive behaviour and/or refrain from challenging behaviour? Also, think about when the reinforcement is provided. If there is a significant time lapse between the behaviour and the reinforcement, the child may not understand why they are being reinforced. If you suspect that your reinforcement system is not effective, you might want to:

- Use a reinforcement inventory to identify other possible incentives that may be more motivating for the child.
- Ensure that the child does not have free access to the item or activities selected as your reinforcement. If they can have it anytime, why would they want to work for it?

- Consider providing the child with a choice of reinforcements rather than selecting one for him.
- Increase the frequency of reinforcement.
Providing reinforcement each time that child displays the desired behaviour (continuous reinforcement schedule), rather than using an intermittent reinforcement schedule.
- Reduce the length of time the child is required to follow their rules and refrain from challenging behaviour before reinforcement is provided.
- Reduce the number of “tokens” the child must earn before being provided with reinforcement.

Consider the possibility that the child does not understand your expectations and/or why reinforcement is being provided (or not provided). If you believe that a child does not fully comprehend the rules, procedures and reinforcement contingencies associated with the Behaviour Support Plan, you may want to outline them visually using objects or pictures (e.g., social script, rule card, choice board, if-then strip).

Think about your expectations. Are you expecting too much too fast? Keep in mind that each behaviour serves a purpose and that the child has likely been relying on the behaviour for weeks, months or even years. Remember, old habits die hard and change may be slower than you hope. If the expectations are too high, the Behaviour Support Plan may actually increase frustration for both you and the child.

Food for Thought

Think about the issues and problems you have tackled in your life (e.g., losing weight, finding the “perfect” job, quitting smoking, decorating your house). Was your first attempt successful? It is important to remember the following when you are attempting to address challenging behaviours...

“If at first you don’t succeed, try, try again.”

Children and youth with developmental disabilities are capable of change. However, their issues and challenges are often very complex, requiring much thought, consideration and, above all, patience.

References and Resources:

Alberta Education. (2008). Supporting positive behaviour in Alberta Schools: An intensive individualized approach. Edmonton, AB: Author.

Alberta Education. (2003). Teaching students with Autism Spectrum Disorders. Edmonton, AB: Author.

Koegel, L. K., Koegel, R. L., & Dunlap, G. (Eds), (1996). Positive behavioural support: Including people with difficult behaviour in the community. Baltimore, Maryland: Paul H. Brooks Publishing Co.

Martin, G. & Pear, J. (2006). Behaviour modification: What is it and how to do it (8th ed.). Upper Saddle River, NJ: Prentice Hall.

4

Module 4: Working as Part of a Team

Unit 1: Family Centred Practice

- Topic 1:** Family centred practice
- Topic 2:** Why use a family-centred model?
- Topic 3:** What is a family-centred model?
- Topic 4:** Building on the family strengths & resources
- Topic 5:** Cultural Differences

Unit 2: Working as a Team

- Topic 1:** What is a team & why are they important
- Topic 2:** Team models
- Topic 3:** Roles & responsibilities of team members
- Topic 4:** Effective communication skills for successful teams
- Topic 5:** Tips for communicating effectively with your team
- Topic 6:** Team meetings
- Topic 7:** Problem solving case examples
- Topic 8:** Developing positive working relationships



*Unit 3: Working with Service Providers
in Your Home*

Topic 1: Hiring

Topic 2: Orientation

Topic 3: Giving feedback to Aides and
managing conflicts with your Aide or
alternative caregiver

Topic 4: Communication/ Problem solving

Unit 1

Family Centred Practice

Family-Centred Practice

Families are the most significant influence in the lives of their children. The family's home is an essential learning environment for all children due to the natural everyday routines and activities. The home offers opportunities for children to learn, make choices and decisions, gain independence and interact with others.. In order to support your children's developmental growth within the family context, parents must be engaged as valued members of the team.

There are many people who are doing good work to ensure that families are part of the planning and decision making involved in

implementing needed services and supports to assist them in meeting their child and family needs. The important question to ask yourself is: "Am I a valued and contributing member of my child's team?"

Historically, a variety of professional models have evolved, each having its own philosophical approach to supporting families. Some models come directly from a medical tradition, others from a counseling perspective, etc. As fields of study and practice evolve, a greater understanding of how to improve support and work with families is gained; new models and professional practices emerge.

Why use a family-centred model?

A family-centred model is fundamentally different from traditional approaches of the past. Approaches to supporting families have traditionally focused on the child with the disability and decisions were ultimately made by professionals. In a family-centred approach, the whole family is the focus and

parents are intimately involved in decision making.

A family-centred model is held as the gold standard for all services provided to families because of the significant outcomes for children and families.

Outcomes of a family-centred model (Dunst, Trivette, & Snyder, 2005).

- Greater parental satisfaction with the services received
- Increased family well-being
- Increased confidence and competence about parents' own skills to support their child's learning
- Increased confidence in their ability to positively influence the future of their child and family
- Increased knowledge regarding their child's development
- Positive judgments about their children's behaviour
- Better overall outcomes for the child

What is a family-centred model?

A family-centred model is made up of a set of values, attitudes and approaches to services for children with special needs and their families. A family-centred model recognizes that:

- each family is unique;
- the family is the constant in the child's life; and
- family members are the experts on their child's abilities and needs.

In a family-centred model, the family works in partnership with service providers to make informed decisions about the supports their child and family will receive. The strengths and needs of all family members are considered (CanChild, 2004).

A family-centred model is both a philosophy and a process of providing services to families. As suggested in the name, the

family is viewed at the centre of the services and decision making. The gift of family-centred model is that families develop the confidence and competence to solve their own problems and they attribute their child's successes to their own skills and knowledge, not to the professionals'.

Professionals who use a family-centred model:

- value parents as the experts on their child.
- support the parents' pivotal role in decision making about services and education plans for their child.
- build on family's strengths.
- individualize and are responsive to parent concerns and priorities.
- honour parent choice regarding program practices and intervention options.
- promote parent-professional collaboration and partnership.
- promote families' abilities to obtain resources and supports necessary for them to care for and raise their children.

Why are family-centred services better?

- Families are happier and more satisfied with services.
- Parents have more knowledge about their child's development.
- Parents feel more confident about their own skills.
- Parents feel more positive about their child's behaviour.
- Their child often has more success.
- Parents have more hope for the future.

(adapted from Dunst, Trivette, & Snyder, 2005).

As part of a family centred team, when making an informed decision it is important to:

- have time to review information and ask questions,
- decide what you feel is best for your child and family, and
- feel confident in your decision.

Building on the family's strengths and resources

When delivering intervention in a family-centred model, professionals help families identify and build on their existing strengths.

When a family has a child with complex needs, many professionals come in and out of your life. As professionals are viewed as "experts" in their field, having specialized knowledge to share, some parents

may feel that the professionals hold more knowledge about your child than you do. Remember, in a family-centred model, you are the expert on your child.

If families hold onto the perception that professionals are the experts, it is the responsibility of the professionals to change this perception in order to have you see and value your own natural strengths and knowledge.

Focus on your family's strengths

Just as the professionals focus on family strengths, it is important that you do as well. Remember:

- All families are unique.
- All parents love their children and want the best for them.
- Every family has strengths and resources.

Think about what you are doing well. Make a list of your family's strengths.

For example:

- You love your children
- Grandma babysits
- Dad bathes the children at night
- You understand what your child wants
- Someone is home with your children after school
- Your family is committed to helping your child
- Your family celebrates traditions together
- Your family has fun together
- There is food and snacks available
- Your children play together
- You have time to spend time alone or with your partner
- Mom is taking a night class
- You have an extended family
- Your family has support from friends and community

Myth: Family-centred services mean that families always get what they want, even when professionals may not support it. (CanChild, 2003)

Fact: In family-centred services, families and professionals work together to reach a decision. Families are provided with information and make the final decision about services for your child and family. Professionals have a responsibility to respect and accept the decision you make. (This is “informed decision making”.)

Cultural differences

Different members of the team may have values and beliefs that are different from your family’s beliefs. Sometimes these values and beliefs are based on cultural differences. It is important to understand that there may be differences so that you can share information with aides and team members working with your family.

Following are some examples:

One belief:	A different belief:
Children should not play with their food because it goes against our religious beliefs.	Young children can play with their food to learn how to eat independently or to develop sensory skills.
Children should be interdependent. It is very important for children to learn to respect elders and get along with others.	Children should be independent. It is very important for children to learn self-help skills, such as eating and dressing.
Oral communication is more important than written communication. Children should be told traditional stories.	Reading is very important for children to have success in school. Children should be read books at an early age.

(Adapted from: Cross Cultural Lessons: Early Childhood developmental screening and approaches to Research and Practice)

Helping service providers to understand your beliefs

Service providers should be sensitive to beliefs and cultural traditions that are different from their own. Many service providers have training to understand different cultures, however, providing services in culturally sensitive ways can be difficult and misunderstandings can happen.

If misunderstandings or problems occur:

1. Explain your beliefs the best you can.
2. Ask the worker to explain their beliefs and expectations.
3. Ask about legal, ethical, and cultural expectations in Canada.
4. Talk about your differences.
5. If you need help, call a Community Facilitator from one of the immigrant serving agencies in your region.

Families are unique

Families are unique, with no single definition of what makes a family. Each family defines family for themselves.

“Families are big, small, extended, nuclear, and multigenerational, with one parent, two or more parents, and grandparents

... We live under one roof or many

... We become a part of a family by birth, adoption, marriage, or from a desire for mutual support ... A family is a culture unto itself, with different values and unique ways of realizing dreams.”

(The Report on the House memorial 5 Task Force on Young Children and Families, 1990)

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Unit 2

Working as a Team

What is a team and why are they important?

Teams who work with children with complex developmental needs are typically composed of many professionals who have a variety of different educational backgrounds. Regardless of the number of members on the team, it is critical that the team shares a common vision, purpose, and commitment towards a desired outcome.

In addition to sharing a common vision and purpose, team members share common tasks. These may include the assessment of a child's current developmental strengths and needs, and the planning and implementation of a program to enhance your child's successful participation within the context of the family, community and school.

Working within a team is critical to ensure you receive:

- opportunities to share knowledge about your child and family centred practice principles, ([link FCP](#))
- opportunities for you to identify current priorities and needs,
- the best possible information and intervention strategies from professionals who have knowledge in areas of child development,
- access to resources needed to implement effective programming for your child,
- diverse perspectives, which contribute to better problem solving of concerns; and
- support for your family.

Team models

The most common team models include: Multi-disciplinary, inter-disciplinary, and trans-disciplinary. While the members of these teams may be similar, the uniqueness of each model is distinguished in the way in which team members interact, plan and carry out their roles and responsibilities.

Team members may include: parents, developmental aide, occupational therapist, speech language therapist, psychology/behaviour consultant, physical therapist, social worker, and clinical supervisor.

Multi-disciplinary teams

- Team members work independently of each other, often side-by-side, sharing space and tools, but focusing on separate activities.
- Your child is not viewed from a holistic perspective but as parts of their development (i.e., fine motor or speech development).
- Services can become fragmented, and information provided to parents may at times be confusing or even conflicting.
- There can, at times, be a lack of communication between team members. The family carries the responsibility to coordinate information and activities.
- Assessment and program planning can be challenging as it may be done in isolation. This can result in target skills not being functional.
- Therapy-/treatment-based model for your child

Inter-disciplinary teams

- Differs from multi-disciplinary primarily in the formal interaction of team members through coordinated scheduled team meetings.
- Assessments done in isolation, but members come together for program planning purposes.
- Decisions and plans remain driven by each member addressing their area of expertise.
- Program suggestions are given to the parent.
- Perpetuates a therapy-based model

Trans-disciplinary teams

- Parents are at the centre of the team.
- Team members share the responsibility for the development of the service plan, which is then carried out by the family and one other team member who is designated as the primary care provider (aide).
- Team members work across traditional boundaries, committing to the time and energy necessary to teach, learn, and work together.
- Assessments are done jointly across disciplines.
- Decisions in the areas of assessment and program planning, implementation, and evaluation are made by team consensus.
- Team members accept and accentuate each other's knowledge and strengths to benefit the team, your child, and your family.
- They share the leadership role or make the decision together as to who will provide leadership to the team.
- The team regularly evaluates its own effectiveness.
- Your child is seen as a whole, and the program plan reflects learning within the context of family and community.
- Members are interdependent – all must commit themselves to assist and support one another.
- Family and child is the focus of the team.

A trans-disciplinary team model is the preferred approach when working within a family centred approach because of the model's commitment to two fundamental beliefs:

1. Child development must be viewed as integrated and interactive.
2. Children must be served within the context of the family, since you are the most important influence in a child's life and are seen as valued and contributing team members.

Teams give families

- an opportunity to share important information about your child,
- help to identify priorities and needs,
- information from different professionals,
- new and different ideas to help solve problems,
- information about intervention strategies,
- access to program resources; and
- support for your family.

When successful teams use a family-centred service model:

- The focus is on your child and family.
- Team members teach and learn from each other.
- Parents receive support to make informed decisions.
- Team members help and support one another.
- Families develop confidence in their ability to care for their child.

Roles and responsibilities of team members

As a family you may be involved in a number of different teams. Many of the team members will remain constant and may work between the different teams. Within a trans-disciplinary team model, all members are responsible to teach and learn from one another.

Therefore, it is critical that the responsibilities of the following members do not fall back to more traditional therapy-based interactions. We will review the team members who may be involved in supporting your child.

Parents – Parents, or primary care-providers, are the most important members of the team.

Parents know their child and family's strengths and needs best. Parents have the greatest long-term influence on their child's development. A parent's information regarding their child is critical to the success of the program. The family ultimately makes all of the decisions regarding their family and their child's program planning.

Community Aide – The community aide is the team member who is central to carrying out recommendations from team members, as well as contributing to program ideas. Other than the parent, the aide is often the team member who spends the most time with your child. The aide's knowledge regarding your child is critical information leading to the success of the whole team. Where other members of the team may specialize in a specific area of development, it is critical that the aide views the whole child and integrates all strategies (language, motor, social and emotional, cognitive, and self-help) throughout your child's daily routines and program plan.

Speech Language Pathologist (S-LP) – A speech-language pathologist helps individuals of all ages to facilitate your child's communication skills. The role of the S-LP is to observe, assess, and recommend appropriate intervention strategies to enhance overall speech and language development in areas of:

- listening and understanding
- making speech sounds and words
- increasing use of words to express needs and wants
- problem solving
- literacy skills
- alternative communication (e.g., sign language, picture boards, technology etc.)
- feeding, eating and swallowing problems

Occupational Therapist (OT) – Occupational therapists address your child's ability to participate in, and build independence in day-to-day activities. These skills include motor control and coordination, sensory motor functioning, as well as skills related to thinking and making sense of their world. The role of the OT is to observe, assess and recommend appropriate intervention strategies in areas of:

- self care (i.e., eating, grooming, dressing, and toileting)
- play skills
- fine motor development (i.e., hand/eye movements, reach and grasp, pencil/paper skills)
- sleep disorders
- guiding behaviour
- sensory motor development

Physical Therapist (PT) - Physiotherapists assist with improving and maintaining an individual's gross motor development, physical independence and overall fitness, health and well-being. A physiotherapist understands how the body moves, and what keeps it moving well. The role of the PT is to observe, assess, and recommend appropriate intervention strategies in areas of:

- modifications to your child's environment
- strengthening and exercising to promote independence
- enhancing movement, including crawling, walking, running, jumping
- participation in active play, monitoring of child's progress over time
- specialized equipment to support motor development and/or access to the environment

Psychologist – Psychologists offers expertise as part of a health- or educational-based team, psychologists offer expertise in areas of mental and emotional development and how this development affects cognitive activities such as awareness, reasoning, judgment, learning, and memory. Psychologists often specialize in behaviour and development throughout the life span. They also look at family, social and environmental factors and provide effective plans to address challenges across a range of health conditions, including developmental disabilities.

Depending on your child's disability, the following are possible team members who may be involved in supporting your child.

Medical Care:

Service Coordinator – If your child is involved with a number of professionals, one member of the team may be designated to coordinate services. This individual takes a holistic view to the team. Typically, the clinical supervisor is the designated team member who coordinates and monitors the overall integration of goals, activities and strategies. She may recommend strategies to:

- ensure all team members, including the family, are working effectively as equal members of the team (Link FCP)
- enhance parent participation (link FCP)
- ensure interventions are evidence-based (grounded in good research practices)
- measure overall outcomes for your child and family
- supervise team members
- coordinate assessment documentation required for funding eligibility

Family Physician - A family physician is a medical doctor responsible for general health concerns. Parents may take children with disabilities to a family doctor on a regular basis to monitor their health and progress. Family physicians work with families to make referrals to specialists for specific assessments or treatment.

Specialists - Specialists are doctors with special medical training (for example, a cardiologist is a heart specialist). If a family physician cannot treat symptoms or requires more in-depth knowledge, a patient will be referred to a specialist.

Paediatrician - A paediatrician is a specialist doctor who treats infants, children and youth.

Psychiatrist - A psychiatrist is a medical doctor who specializes in assessment and diagnosis of mental health problems or psychiatric disorders. Psychiatrists work with adults or children. A psychiatrist may provide individual, family or group counseling and can also prescribe medications.

Neurologist - A neurologist is a doctor who specializes in the assessment and diagnosis of neurological disorders (the brain and spinal cord, and central nervous system). A neurologist provides treatment and can prescribe medications.

Nurse - Nurses work with doctors to provide patient care. In a hospital, doctors make most of the decisions about medication and treatment, and nurses typically provide this treatment. Nurses may work in hospital clinics, schools or in the community such as Community Health Clinics.

Public Health Nurse - A public health nurse helps people in a community setting, at a community agency or by visiting your home. A public health nurse gives routine vaccinations starting when your child is two months old. A public health nurse may ask questions about your child's development. A public health nurse may suggest early intervention services.

Dental Care:

Dentist - A dentist is a doctor who specializes in the care and treatment of teeth and gums. A dentist provides regular dental check-ups, and treats minor damage to teeth (like cavities) or may treat more major damage to the teeth and gums.

Orthodontist - An orthodontist is a specialist dentist who corrects uneven teeth and jaw problems with braces, retainers, or other dental appliances. An orthodontist may refer you to a dental surgeon if surgery is required.

Social Care:

Social Worker - A social worker is a professional who is trained to support people with their emotional, social or physical needs. A social worker helps families find resources and services in the community. Social workers may work in a hospital, with an agency or within a school setting.

Behavioural Specialist - A behavioural specialist assesses the possible causes of behavioural problems and develops programs to help children learn acceptable/positive behaviours.

Educational Care:

Classroom Teacher - is a trained professional with a university degree in education. She may teach many subjects or just one subject area. A teacher is responsible for developing and carrying each student's IPP within the school setting.

Educational Assistant - works under the supervision of one or more teachers. She may work with individual students or groups of students to help with learning or behaviour.

Resource Teacher, Specialist or Strategist - is a teacher who has expertise and skills in special education. Typically, the resource teacher or specialist provides support to the classroom teacher to develop and implement the IPP or instructional plan and may be the designated team member who coordinates the education team and monitors the program plan.

School Principal - is the most senior person in the school. The principal is responsible for decisions that govern the school, as well as hiring and supervising teachers.

Vice or Assistant Principal - assists the principal. The vice principal may be responsible for teaching, student discipline, and overseeing school events.

Guidance Counsellor - is a professional who has training in social work or counselling. This person helps students work through school-related problems and helps students to make decisions about education and life goals. They may also help students with emotional or other personal problems.

School Psychologist - is responsible for psychological assessments of students who have learning and/or behaviour problems. The school psychologist will make recommendations to the school and parents.

Family Counsellor - is a professional who helps families with their emotional health and helps families to resolve conflict. He may work with the family together, or see family members separately.

Respite Worker - is responsible for the care and supervision of a child with a disability, so that parents may have a rest or break. A respite worker may be a friend, a student, a family member or can also be hired through an agency.

Food for Thought

Take a piece of paper and draw three columns. Take a moment to jot down the “strengths” you bring to the team in one column, and your “needs” (the knowledge or skills you hope to develop) in the second column. In the third column, make a list of all the possible steps you can take to ensure you receive the support to meet your learning needs in order to feel confident and competent to fulfill your role within the team.

Effective communication skills for successful teams

One of the most critical aspects to working effectively in any team is communication. Effective communication refers to the interpersonal skills and behaviours that build, support and maintain the positive relationships that are critical to carrying out the work.

Effective communication begins the very first time we meet with the team or a member of the team.

“Communication reflects the value and the respect we hold for the person with whom we are communicating. We communicate with others to convey important information, feelings and plans for the future.” (CanChild, 2003)

Six important components to achieve the team communication we desire:

1. Listen

Active listening is a skill that lets the person who is talking to you know that they are being heard. We can demonstrate this in a number of verbal and non-verbal ways:

Non-verbal:

- Face the person who is talking to you.
- Make eye contact.
- Try to focus on what the person is telling you; stay present. Try not to let your mind wander.
- Lean forward and relax.
- You may want to nod your head to indicate you are listening. This often comes naturally.

Verbal:

- Paraphrase – clarify what the person has said to you to make sure you have understood her correctly.
- Check in to make sure you have it right.
- Ask questions if you are not sure.

2. Empathy and understanding

We communicate empathy by listening as well as acknowledging how the person is feeling. Acknowledging feelings requires sensitivity and an ability to understand the situation from the perspective of the other person. We often refer to this as “walking in the other person’s shoes.” What would I feel if I was in his place? Feelings are based in our emotions. Feelings

might include: frustration, happiness, fear, sadness, anxiety, concern, anger, hopefulness etc... It is important that team members don't assume they know how the other is feeling, but that we check out if we have heard the intent of the communication accurately.

Examples of statements of empathy:

- That must be very frustrating for you!
- It is always difficult to wait for things to change. Are you concerned about what might happen?

3. Ask questions

It is important to ask questions to be sure you have understood your team member correctly. Ask questions that are open ended. These are questions that cannot be answered with a simple “yes” or “no”. Questions should start with “What?” or “How?” Questions like this encourage communication and provide more information to allow greater learning and understanding in a particular situation.

Notice the difference in potential information received between closed or open questions

Closed Question	Information Obtained	Open Question	Difference in Possible Information Obtained
Consultant: Are you taking your child on a walk each day?	“Yes or No”	How are the daily walks working for you and your child?	
Parent: Do I need to show my child the picture for each activity?	“Yes or No”	Can you explain the purpose of showing my child a picture during each activity?	

Tip: One of the most helpful questions to ask someone when you don't understand where he or she is coming from is: “Help me understand how ...”

4. Summarize the conversation at the end

This will provide additional clarity on the discussion.

Example: “Just let me summarize our decisions today. I am going to try the new activities we just talked about, and you are going to call the Speech Therapist to see if she has any more ideas.”

5. *Don't make assumptions*

Don't assume what another team member is thinking or feeling. Ask for clarification because sometimes we can make assumptions that are not correct. For example:

Discussion:

Mary (parent) called Christa (Occupational Therapist) on the phone today and asked her if she could bring the materials they discussed using by the family's home today. Christa responded quickly by saying: "No, I can't and I'll call you back."

Assumption:

Mary assumed Christa was upset with her about something because she appeared to be sharp in her communication on the phone.

Response:

How might you respond to Christa to check out your assumptions? After brainstorming all possible options, choose one option that you feel might be the most successful to confirm the message and intention of Christa's message.

6. *Be precise, relevant and direct*

Speak in a clear, concise manner, use facts, and be direct, while maintaining respect. Stay on topic. Make comments that are related to the conversation that is occurring.

Barriers to communication within teams:

- Members of the team may not be clear on the role of each member and what they can expect from each other.
- Members may work from different values and priorities (i.e., some may not view the family as an equal partner on the team who have the ability to make their own decisions)
- Members of the team may have had some negative experiences on other teams (e.g., communication, boundaries). They may come with the perception that this is going to happen on their current team.
- A system may not be in place to ensure that all members of the team are communicating on a regular basis. This includes determining times and places that work for all members of the team.
- Communication is not adapted to meet the needs of all team members. (e.g., literacy level, English as a Second Language).
- Team members may not have access to a resource person to support them in their efforts to work through team barriers to communication.

When barriers to effective communication occur, confusion within teams can very easily be experienced. Once confusion through poor communication happens, it is much more difficult to re-establish a positive and effective team.

Tips for communicating effectively with your team

Planning for an appointment

- Organize information about your child. (You may want to use the Family Journal from the Alberta Children's Hospital website).
- Create a file.
- Write down a list of questions you want to ask and concerns you want to talk about. You can use the Appointment Information Form.

Helpful questions to ask before the appointment

- What is the job or specialty of the person you are meeting with? Can the person you are meeting help you with the concerns you want to talk about?
- Should you bring your child?
- Will there be difficult tests, treatments or assessments that you might want to prepare your child for?
- What records or documents should you bring to the appointment?*
- If your first language is not English, do they provide interpreters?
- How long will the appointment be? (This will help you to make arrangements for transportation or child care for your other children.)
- Is there help with child care or transportation?
- Are there fees for the services? If so, are there subsidies or funding?

*The following documents might be necessary:

- Personal identification. For example, a driver's license or passport, Citizenship documents
- Alberta Health Care cards for you and your child
- Alberta Children's Hospital card (if your child has been to ACH before)
- Names of doctors and professionals your child has been to, their specialties, and their contact information (like a Neurologist or a Physiotherapist)
- A list of medical treatments or therapies your child has had, like surgeries, scans, x-rays, or physical therapy
- A list of medications and doses that your child is currently taking, or has taken in the past
- Immunization records
- Birth records for your child
- Information about your child's development, like when he began talking, walking and reading

- Records of assessments or educational tests
- IPP (instructional) plans and records
- Progress reports or report cards
- Any correspondence or letters between you and the school
- Notes from previous meetings
- List of community support services like advocates and community agencies
- Extended medical benefits cards (for example, Blue Cross)
- If you are asking about financial support or subsidies: proof of family income, like pay stubs or income tax returns

Questions to ask at the appointment

- Talk about concerns that the team member might be able to help with.
- Ask them to explain any treatment or test they suggest or arrange.
- Ask about the benefits and side effects of any drugs they prescribe
- Ask if there is any cost for treatments, services or tests they recommend. If the expense is a concern, ask about lower cost alternatives, or if they know of any available subsidies.

Keeping track of information

Parents meet with many service providers and teams, and you will gather a lot of information from meetings with your child's different teams. It may be difficult to remember everything. Some things that might help:

- Take notes when you are talking with a service provider. Get the correct spelling of medical words.
- Ask the team member to explain information in a way you can understand.
- Record follow-up appointments and meetings in a calendar.
- Keep all information organized so documents are easy to find.

Working with interpreters

It is often difficult to communicate with team members. If your first language is not English, it is even more difficult (even if you speak and read some English). It is useful to have an interpreter attend meetings. When you schedule a meeting with a service provider, ask them if it is possible to have an interpreter to be present. Ask if there is a cost. (Many programs provide interpreter services at no cost, and some may be able to help you find funding if there is a cost.)

There are different types of interpreters. For some appointments, you may want to take a friend or family member who has a good understanding of English. It is not a good idea to take one of your children as an interpreter as the information can be very complicated and professionals will look to the parents to make decisions. Many hospitals have interpreters available. They will need to be booked at the time you book your appointment.

Before you do this, you should consider:

- Will you be discussing personal information that you want to keep private (like problems with money or conflict in your relationship)?
- Are you meeting with a health professional who might use complicated medical language?
- Will you be signing important documents, such as legal or financial agreements? It is important that you understand these papers clearly before signing.

If any of the above applies, you should use a Professional Interpreter.

Some parents do not want to use an interpreter because they worry the interpreter may share personal family information with others in their community. A Professional Interpreter must follow a code of ethics. A Professional Interpreter must:

- Provide accurate and truthful information. An interpreter must not add, leave out, change or explain information.
- Stay neutral and not take sides or give advice. An interpreter is not part of the discussion, they only tell you and the service provider what each of you is saying.
- Maintain confidentiality. An interpreter is legally bound to not tell anyone information about a meeting. She must destroy any notes taken during the meeting before she leaves the meeting.
- Have proficiency, which means understand and speak very well, in both languages.

Example**Working with an Interpreter – Two Stories**

Micah is seven years old. Last month he had a speech assessment at school. He also saw an ENT (a doctor who treats diseases of the ear, nose, and throat). The doctor sent Micah for an x-ray. A nurse from the ENT clinic at the Children’s Hospital called Micah’s mother, Ayah, and scheduled an appointment for her to meet with the ENT doctor.

Story 1

Ayah went to the doctor’s office alone. She was nervous.

Doctor: “Thank you for coming in, Mrs. Adin. I have the results from Micah’s speech assessment and the x-ray. I would like to schedule Micah for an adenoidectomy and a frenectomy. I have made a referral to a plastic surgeon. The waiting list is about six months long. If the plastic surgeon agrees, we can do both surgeries at the same time. Do you have any questions?”

Ayah: “No... thank you.”

Ayah left the doctor’s office quickly. She was scared and confused. She did not know what to do.

Story 2

Ayah was nervous when she went to the doctor's office. She was met by a woman who told her she was the interpreter. The interpreter explained her job. She told Ayah that everything said in the doctor's office was confidential (private).

Doctor (Interpreter): "Thank you for coming in, Mrs. Adin. I have seen the results of Micah's speech assessment and x-ray. I would like to schedule Micah for an adenoidectomy and a frenectomy. I have made a referral to a plastic surgeon. The waiting list is about six months long. If the plastic surgeon agrees, we can do both surgeries at the same time. Do you have any questions?"

Ayah (Interpreter): "Yes, I have many questions. Can you please write down the name of the two surgeries my son needs?" She handed the doctor the Appointment Record Form.

Doctor (Interpreter): "Certainly. Adenoidectomy and Frenectomy."

Ayah (Interpreter): "Can you explain in simple language? I want to understand."

Doctor (Interpreter): "Yes. An adenoidectomy is a common surgery. The adenoids are removed while the patient is under a general anesthetic. It will help Micah to breathe and talk better." He shows Ayah a picture. "A frenectomy is a simple procedure. Sometimes the tissue under the tongue is attached too close to the end of the tongue. It can cause speech problems. This is called "tongue-tied". Clipping the tissue will release the tongue. This is usually done in a dentist's office. We will do it here since Micah is already having surgery. We hope it will help Micah to speak more clearly."

Ayah (Interpreter): "Will the surgery be painful?"

Doctor (Interpreter): "There is usually only a little pain. He can stay in the hospital for a few hours. He will likely feel fine in two to three days."

Ayah (Interpreter): "What is our next step?"

Doctor (Interpreter): "The nurse will call you with a date for surgery. You and Micah may want to attend a "Pre-Surgery Orientation" session here at the hospital. It helps children and parents know what to expect on the day of surgery."

Ayah to Interpreter: "Could you help me book a time to go to the orientation? Could you come with us?"

Interpreter to Ayah: "I'd be happy to."

Ayah left the office with the interpreter. They scheduled a time to go to the orientation. Ayah was not so worried. She was thankful she had remembered to book the interpreter.

Your Turn

Reflect on the approaches used in the two stories and their different outcomes. How can you utilize the strategies when you prepare for your child's next appointment or team meeting?

Team meetings

Team meetings are another time that you may be involved with different members of the team. Team meetings provide an opportunity for all team members to contribute to the direction of the child's and family's program. In order to ensure that you are best able to contribute, be prepared – families often feel more confident if they are prepared.

Before the meeting...

Get organized

- Organize information about your child. Create a file.
- Write down a list of questions you want to ask and concerns you want to talk about.
- Use the Appointment Information Form.

Get information

- Understand the purpose or goal of the meeting.
- Find out who will be attending the meeting.

During the meeting...

- Provide information about your child.
- Provide knowledge about your family.
- Ask for more information when you don't understand something.
- Ask questions and stay informed about your child's progress.

Elements of a successful team meeting

- Team members are present and on time.
- The meeting starts and ends on time.
- There is a facilitator and a note taker.
- Team members understand the purpose and goal(s) for the meeting.
- Members use effective communication skills.
- Members are invited to contribute to the discussion.
- All participants have time to speak.
- Problem solving steps* are followed when appropriate.
- There is a summary of the discussion.
- Members agree on actions or follow up to be taken.
- Team members take responsibility for actions.
- All team members receive a copy of the meeting notes.

Problem solving

It is natural for teams to face challenges from time to time for a number of reasons (e.g., different opinions that may lead to conflict, members not following through on expected roles or responsibilities, inappropriate expectations of others, false assumptions made through ineffective communication etc.).

How well a team is able to engage in problem solving processes will define a team's future success. A commitment to following a problem solving process increases the likelihood for creative solutions. Below is one problem solving model to help teams get through any barriers or road blocks.

Seven Steps to Effective Problem Solving

When participating in a problem solving process, it is best to follow a step-by-step process to review the issue from all perspectives. It is also helpful to write down responses to track the thinking process of team members. Read the steps below, and then review the case studies that follow to walk through and practice how this process might look on a real team.

- 1. Define the problem** - This involves a summary of the current challenge/issue from the perception of each of the team members involved. This is the most challenging aspect of problem solving to ensure the perceptions of others have been heard. This step will take the most amount of time for the team.
- 2. Brainstorm ideas** - Brainstorming is a process whereby all individuals share all possible options, thoughts, and opinions that may be helpful to working through a problem. It is critical that within the brainstorming process, all ideas count, no matter how strange they may seem, ideas are accepted as equal with no judgments, comments, or critique. Brainstorming is about being creative. Write down all ideas.
- 3. Evaluate each idea** - Review the brainstorm list. Cross out the ones that everyone feels is not an option. For each idea that you feel is an option, write down the PROS and CONS of each option.
- 4. Choose** - From the remaining ideas, choose one or a combination of ideas to begin to try.
- 5. Make an action plan** - Decide who will try what idea, beginning when, and for how long before the team evaluates the effectiveness of the plan.
- 6. Implement the plan** - Follow through on the interventions and actions agreed upon in the plan. Record what is done, and the response to the interventions.

7. Evaluate the effectiveness of the plan - For many teams it is easy to carry on with the day-to-day activities and not evaluate how effectively the new plan is working. Evaluation might include the following reflections:

- Did the plan work?
- Are there parts of the plan that are working?
- Do we need to do some more problem solving? If so, the team may have not accurately defined the problem. Going back through each step may be helpful.
- If change is not apparent, it may be important to review your definition of the problem and ensure that the problem has been targeted accurately. Has the problem changed?
- Are the brainstorming ideas the best fit?
- Taking time to complete this final evaluation step will help the team address other challenging situations in the future.

Problem Solving Scenario

Sara is a five-year-old girl who lives with her mother and 3-year-old brother. Sara loves listening to music. She enjoys it when her playgroup sings songs and will sometimes sit for a favourite song and imitate some actions. Sara also likes to look at books with pictures. Sara is using about 10 words and a few signs to communicate with others. Sara loves to run. She loves bare feet and likes the feel of different textures when walking or running. Sara has a difficult time sitting for too long. She needs to get up and move often. She has a favourite track suit that she likes to wear every day. Strong smells and loud noises upset Sara. When Sara is upset, she bangs her head, cries and screams. Sara likes other children and will sit beside them for short periods of time while they are playing. If there are too many people in a room, Sara will become upset and start to tantrum.

More recently, it has been very challenging to encourage Sara to put anything on her feet to go outside.

What is the current problem? While there may be many challenges in the scenario worthy of addressing, the parents and aide are choosing to address the problem of getting shoes on Sara so she can participate in her daily routines.

Mom's issues	Aide's issues
Sara might become sick as her feet are getting cold.	Sara is screaming and banging her head when the aide tries to get her to put her shoes and socks on.
It is hard to carry Sara when mom also has Sara's little brother with her.	The aide's back is getting sore from carrying Sara.
It is hard to get out in the morning because Mom spends a lot of time trying to get shoes and socks on.	The aide is avoiding following through on any activities in Sara's program that require them to go outside of the house.
Other adults stare at Sara's mom when she is out in public and Sara has bare feet in the winter.	
It is important to identify all of the issues; the issues are not the problem. Once all issues are identified, team members must agree on one shared understanding of the problem in order to proceed in addressing it.	

Steps of problem solving	
<p>1. Define the problem Choose an agreed upon understanding of the problem to work from for problem solving process</p>	<p>The shared understanding of the problem is: If we are to take Sara outside, for most months of the year, her feet need to be covered from the cold.</p>
<p>2. Brainstorm ideas with the team **</p>	<ul style="list-style-type: none"> • Wrap Sara’s feet in a blanket • Buy a snow suit with feet • Try out different socks • Try slippers • Let Sara pick out her own shoes • Try to find shoes in a colour Sara likes • See if Sara will wear shoes that are big for her • Massage Sara’s feet before you put socks and shoes on • Stay inside
<p>3. Evaluate each idea PRO/CON EACH IDEA **</p>	<p>1. Wrap Sara’s feet in a blanket</p> <p>Pros <i>Sara will be happy</i> <i>Sara’s feet will be warm</i></p> <p>Cons <i>Sara is very heavy</i> <i>The adults will get a sore back</i> <i>There will not always be an adult to carry Sara</i> <i>Sara is not learning what she needs for the future</i></p> <p>Go on to pro/con each idea</p> <ol style="list-style-type: none"> 2. Buy a snow suit with feet - 3. Try out different socks - <i>possible</i> 4. Try slippers - <i>possible</i> 5. Let Sara pick out her own shoes - <i>possible</i> 6. Try to find shoes that are a colour Sara likes - <i>possible</i> 7. See if Sara will wear shoes that are big for her - <i>possible</i> 8. Massage Sara’s feet before you put socks and shoes on - <i>possible</i> 9. Stay inside
<p>4. Choose best ideas</p>	<p>Try different socks, try slippers, and let Sara pick out shoes. Massage Sara’s feet before you put shoes and socks on.</p>
<p>5. Action plan</p>	<p>Mom will take Sara shopping and try on some slippers. Sue (aide) will give Sara the choice of shoes or slippers when going outside. Mom and the aide will massage Sara’s feet before putting shoes and socks on. Christa (OT) will look for socks with no seams.</p>

Steps of problem solving	
6. Implement the plan**	<p>We will try this for 2 weeks, and then meet again.</p> <p>It is helpful to document the decisions that the team has made together. Documentation can be done by jotting down decisions within a daily journal or notebook used by the team. In doing so, the action plan is communicated to all team members and is likely to increase the commitment of members to implement the plan.</p> <p>Set a date to evaluate the implementation of the plan.</p>
7. Evaluate	<p>Sara did not tolerate her new slippers and giving her choices did not help. She will wear the socks without seams.</p> <p>Question for team: Is this solution meeting the issue? Is it necessary to brainstorm more ideas?</p>

**** Remember, if you don't have time to go through this whole problem solving process, at the minimum do steps 2, 3 and 6. However, if the problem continues to exist, go right back to # 1 and use all of the steps, as you may not have correctly identified the real problem.**

Your Turn

Complete the problem-solving scenario below using the 7 steps outlined above.

You have been working with a particular team for a few months. You begin to feel more and more frustrated as you are working with your child's aide and seldom see other team members.

You look forward to visits from team members to talk about the program and get feedback on how your child is doing. As team members visit, the expectations to implement more intervention strategies for your child's developmental goals continue to increase. You are doing the best job you can, but feel that you can no longer keep up with the expectation from the team. At the next team meeting, you decide that it would be good to discuss your concerns with the team members. At the meeting you choose to use the 7 steps of problem solving to guide your discussion.

What is the current issue? All team members discuss the potential issues.

Mom	Aide	Speech Therapist	OT
The aide seems overwhelmed. She appears tired and less focused at work	The aide has many suggestions from each therapist and does not have time to do them all	Communication is very important for the child and it is critical that the activities be followed	The OT does not feel that she has given that many suggestions and the aide should be able to follow through on them
Your child seems overwhelmed	Some of the activities seem to contradict each other	The SLP and the OT have not had a chance to discuss their ideas with each other for a long time	The SLP and the OT have not had a chance to discuss their ideas with each other for a long time
Your child is not enjoying some of the activities	Some ideas are not working		
You do not understand why some activities are being done	The aide cannot contact the therapists in a timely manner		
	The aide does not understand why some activities are being done		

Steps of problem solving	
1. Define the problem Choose an agreed upon understanding of the problem to work from for problem solving process	The problem is: The team has not been able to meet together for several months to discuss the program plan.
2. Brainstorm ideas with the team **	
3. Evaluate each idea PRO/CON EACH IDEA **	
4. Choose best ideas	
5. Action plan	
6. Implement the plan**	
7. Evaluate	

If you don't have time to go through this whole process, at the minimum do steps 2, 3 and 6. After this, if the issue still exists, go back and use all of the steps.

Developing positive working relationships

When an aide is working in your home, the environment can often become more casual in nature than a clinic or school setting and relationships can become more personal. Each of these factors can create increased challenges in maintaining professionalism for the aide and cause concerns for families at the same time. For all team members, the following may be important.

1. Keep professional boundaries

When professionals work in a family's home, boundaries can get blurry. While it is very important to build a positive relationship with your worker, this is very different than forming a friendship. Sometimes when the work relationship is finished, friendships are formed, but families and workers need to be careful about keeping professional boundaries while working together.

Here are some examples that may start to cause difficulties:

- Sharing personal information not related to your child (i.e., relationship issues, personal problems).
- Asking the worker to stay beyond their scheduled time to provide more support.
- Requesting tasks that are not a part of the worker's job description, roles or responsibility. (i.e., childcare, starting supper or stopping at store for milk for the family).

2. Confidentiality

Confidentiality refers to the right of privacy of all information pertaining to a child and family. An agency is required to have policy and procedures pertaining to the current legislation. Aides should be familiar with agency policy to guide their professional practices.

Further information regarding the Freedom of Information and Protection of Privacy (FOIP) can be obtained by searching www.foip.alberta.ca

3. Deal with issues in a timely manner

If something is bothering you within the team, deal with the issue as quickly as you can. A good general rule is to give yourself a day to reflect and, if the issue is still a concern, deal with it directly with the person involved within the next 48 hours.

4. Communicate with team members directly

Do not talk about other team members in their absence. If you have a concern or issue with a team member, talk to him or her about it directly. Do not engage with others if they initiate talking about a team member in their absence. Model direct communication by suggesting that they share their concerns only with the supervisor or with the person directly.

5. Treat your team members with respect

It is important to ensure that team members treat others as they would want to be treated themselves. Look for the positive aspects of the team. Focus on the individual strengths of your team members, take time to acknowledge the support your team has provided you, and remember to use effective communication and problem solving skills when issues arise.

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Unit 3

Working with Service Providers in Your Home

Hiring

Hiring an Aide can be a complex and challenging process. In some areas, as in urban centers, there are agencies that parents can work through to find Aides. In rural areas, parents often hire Aides independently since there may not be any Service Providers. Both approaches have benefits and challenges.

Benefits of using a Service Provider:

- Initial screening and paperwork is completed.
- Aides often have basic orientation and may have continuing professional development.
- Aides often have a team or ready access to a team.
- Supervision of the Aide and program is available.
- Payroll is taken care of by the agency.

Benefits of hiring independently:

- Parents may have more choice in the individual hired.

Challenges of using a Service Provider:

- There may be a waiting list.
- You may need to be part of a program approach that the Service Provider adheres to.
- You may feel that this is more intrusive.

Challenges of hiring independently:

- It may be challenging to find people qualified to be an in-home Aide.
- It is time consuming to post job ads, interview and orient new people.
- Parents are responsible for payroll (Tax deduction and employer portion, Employment Insurance, Canada Pension, vacation pay).

Parents using either approach will attest to the fact that hiring is not easy. Several organizations have information available to assist you in this process:

FSCD website provides information regarding hiring Aides at <http://www.child.alberta.ca/home/1272.cfm>

AAFL provides Strengthening Family Facilitators in their Supporting Communities Program. You can get more information at www.aacl.org

Orientation

Once you have hired an Aide to work with your child, you will need to get him or her ready to do the work. Orienting an Aide will take different forms depending on how your Aide was hired. For example, Aides hired by an agency or service provider will often have an orientation that includes an overview of disabling conditions, approaches and strategies. Some agencies provide ongoing workshops and professional development

while others do not. If you are hiring an Aide independently, you may need to provide this information as part of the orientation.

No matter how your Aide was contracted, you will need to orient him or her to your home, your family and your child. Families will manage this in their own ways, but generally providing an orientation with some expectations and guidelines is helpful to beginning your relationship.

Things to consider in an orientation:

- Orientation to the specific disabling condition
- Orientation to the approach used in skill development
- Orientation to your child and her specific strengths and challenges
- Orientation to your home – your routines and expectations
- Discussion about how support may best be accomplished, including times, places, activities

Remember that many parents will find the addition of an in-home Aide and other team members intrusive. Aides may be present at family times (e.g., meals) and more intimate times (e.g., bed time or mornings). You will need to do what you can to feel comfortable while, at the same time, making the Aide feel comfortable.

One of the challenges of having a child with special needs is learning how to deal with all of the people who come into your life

and your home (whom you haven't necessarily invited). Some parents and families are not comfortable having Aides or respite care in their homes and have planned alternatives. For example, using out-of-home respite when the child is old enough or using community-based recreational services as a form of respite.

I never liked to have people in my home, particularly when I was at home, so I chose not to do an in-home program and did all-day centre-based programming. The last

year of their PUF funding, they went to an all-day kindergarten program. There weren't home-based early intervention programs at that time, so starting kindergarten was more typical. As soon as the boys were old enough, I chose to do most of my respite out of home. I have long term respite providers that have worked very well for my family. I use recreational activities and transportation (Access Calgary) as a component of my respite. You can get an extra 1-2 hours while your child is being transported to and from their activity so that a 2-hour program becomes 3-4 hours of respite time.

Other parents need in-home supports and cope by setting protocols or guidelines in place. For example, clarifying which areas of the house an Aide can work with the child in, times she is welcome, schedules, and routines.

Even with protocols and routines in place, parents may feel uncomfortable. One common concern is what to do when the Aide is there. They wonder whether it is appropriate to go out, to watch television, or read a book. Often the answer depends on the reason the Aide is in the home. If the Aide is engaged in skill development, there may be an expectation that parents be involved. For example, FSCD funding includes an expectation that parents are involved in skill development. Respite care is different and the purpose is for parents to have a break, so the terms may be different for respite care providers. Be sure to discuss the parameters and expectations with your service provider and Aide regularly as things may change.

Here is one set of hiring and employment protocols used by a parent in a rural area.

HIRING & EMPLOYING AIDES

In-Home Employment Protocols

Prepared by: Micheline Lambert-McFadden, March 2011

At three years of age (2006), our son was diagnosed with ASD/ADHD. We needed two weeks to comprehend the full impact of our (it affects the whole family unit) diagnosis; shortly thereafter, we took the 'bull by the horns' and headed our son, us and his little sister down a new path of evidence-based treatment therapy in hopes of enhancing our son's overall development. NOTE: It's never too early or too late to start therapy/intervention.

Entering into our fifth year of evidence-based developmental therapy, we feel we are now in a position to share our experiences and what we have learned with new parents combating their child's diagnosis.

Listed below (in no particular order) are protocols we have found beneficial to follow for consistency for our son.

Hiring Protocols

1. Ensure new employees' (therapists') qualifications are correct and official. Contact universities, schools, etc. and ensure stated education is correct.
2. References: Contact a minimum of three references (professional, schooling, personal), speaking preferably in person or by phone. Do not rely solely on written references.
3. Arrange a 'meet and greet' between you, the applying therapist and your child to get a sense of it being a good fit. Note: Listen to your intuition and pay attention to whether or not your child responds favorably to the applicant and vice versa.
4. Create a 3 – 5 day cross-training and/or trial period with new applicants to ensure that the individual can work together with your child and other team members.

Create an opportunity for a new applicant to meet with existing therapist team members. Provide and review IPP goals to ensure new applicant

Giving feedback to Aides and managing conflicts with your Aide or alternative caregiver

There are differing needs for support over the years in the life of a child with a disability. The two primary areas where an Aide will work with your child will be 1) In home and 2) out of home. Let's look at both these areas and consider the role of Aides in relation to your family.

The intensity of supports required is directly related to the needs of the child and family in relation to the disability. For some children with severe physical and developmental disabilities, greater supports may be required. The level of support required for your child will be assessed and determined by the professional team working with the family. The needs between families differ and are assessed on an individual basis. A family can choose whether they want to have an Aide working within their home, if that level of support is

required. There may be situations where it is strongly recommended by a professional that an Aide work with your child in the home in order to support her development. An in-home Aide is not always required and families do have some choice about whether this type of support will work for them.



In-home Support

In-home support is an important resource for families with a child with a disability. Some of the reasons your child may require an Aide are related to physical disability, emotional and behavioural concerns, the need for constant supervision due to a medically disabling condition, and to provide respite in the home. When an Aide is in your home, his role is to work with your child, one-to-one, for a specific period of time. The work of the Aide is child-focused, meaning that he will provide support related to the developmental needs of your child. An Aide will work on goals that have been identified as important to support the growth and developmental needs of your child.

The amount of time required for in-home support will differ according to the needs of the child. A health professional that has assessed your child will discuss this with you and make a recommendation and referral



for service. Once a referral has been made, the agency will contact you to make an appointment for a home visit to meet you and your child, and determine if services can be offered. An Aide will be required to keep records of her visit and to document her work. There should be a mechanism for communication with the supervisor of the Aide in order to evaluate the experience, to determine if it is working or if modifications need to be made in the arrangement.

*One important question you must ask yourself as a parent is whether you can take on the multiple roles associated with parenting and being primary therapist of your child. In-home support is meant to be therapeutic for the child and of benefit to the family. It may help to talk with other parents who have worked with in-home Aides about their experiences when considering this type of support. An in-home Aide can take a lot of pressure off a parent who has other children to care for and is not always able to do everything for everyone within the family. It takes courage to accept help and be willing to try the experience of an in-home Aide for your child. It can be hard to let someone you do not know into your home to work with your child. The only way you will know if this support works for your child and family is to try it out. A parent and an Aide need to have regular communication about the needs of the child and discuss/consider any changes that have taken place between visits. If your child has been ill for example, it is important to let the Aide know. A brief check-in between the Aide and the family at the time of the visit offers a way to provide an update.

Communication/Problem Solving

The primary focus of having an Aide or alternate caregivers to provide respite (in home or out of the home) is to meet the needs of the child with a disability. Although the help is necessary and important, there are times where problems can arise. Some families struggle with a number of adjustments and bringing a new person into the home can offer help, hope and reduce stress. Having an Aide in the home can provide time for parents to take care of other family responsibilities. Alternatively, out-of-home care can also provide

much needed respite, and short breaks are important for stress reduction on parents.

Clear and open communication is the primary tool for making relationships with Aides and alternative caregivers work. Clear communication requires openness and transparency. Parents need to establish a mechanism to communicate with their helpers and professionals involved in the lives of their children.

Strategies for open communication with others supporting and caring for your child can include:

1) A Communication Book – a binder or a book that has a description of your child and includes information about the disability, care needs, likes and dislikes, emergency protocols and contact information for family members and the family doctor. Both the parent and the Aide or caregiver can use this tool quite effectively. Identify your expectations around written communication and the information you would like written into the book. This can be established through a conversation with the Aide or caregiver at the outset of the relationship. A communication book also helps you to keep track of any changes and illnesses and identify what works best for your child.

2) Regular Meetings and Updates – When an Aide or caregiver is in your home, he has to be made aware of the needs of the child. As the support is intended to be child focused, the conversations between the Aide or caregiver and parents should be brief and clear, identifying the needs of the child for the day. It is easy to get distracted or off topic and later feel resentful that too much time was spent talking when there were other things to do. This can happen unintentionally, but boundaries need to be set around these brief meetings to keep the focus on communicating the daily needs of the child, passing on health-related concerns, and discussing what the activities are going to be for the period of time in the home.

3) Establishing Boundaries – Clearly identify the means of communication and your expectations of an Aide or caregiver. Sit down and have a conversation at the outset of the relationship about your ideas, goals and hopes for this type of support. Be very clear about times and meetings. For example, when the Aide or caregiver arrives to offer support for a 3-hour period, plan to use the first 10 minutes to have a meeting about the needs for today. If possible, write a list and be prepared to present this information prior to the arrival of the Aide or caregiver. This way you won't forget what you wanted to tell this person because you were distracted by something. Having a routine about the exchange of information and time limits for meetings is an effective way of establishing boundaries.

4) Problem-Solving Strategies – What happens if there is a problem or breakdown in communication with an Aide or alternative caregiver? There are many ways that this can happen. Every parent believes that no one else can care for their child better than they can. When a child has a disability, families establish particular rhythms and routines that work best for them. It can be very stressful in a family if an Aide or alternative caregiver does not fit with the family routines, or if there is a perception that she is not working effectively in meeting the child's needs. Communication can break down when parents find it difficult to raise their concerns to the Aide or caregiver. There can be a real fear that the caregiver may not come back and you then have to start over with someone new. Letting concerns go without addressing them tends to lead to more serious problems however.

If there is a breakdown of communication with the Aide or caregiver, begin with a meeting to discuss these concerns. Even though this may be difficult to do, it is important to have a meeting as soon as possible after concerns arise. You can ask another family member or friend to participate in this meeting. If the concern is serious enough that you feel you must contact the supervisor of the Aide or caregiver, do so. The supervisor is someone who can provide an objective viewpoint and usually has known the individual for some time. It is important that these communication breakdowns be dealt with in order to problem solve, identify strategies to resolve the problem, and establish boundaries about what works and what doesn't work in your family. There is no perfect solution to these problems.

However, the central focus must remain on the child and assuring his needs are met. In circumstances where the problems cannot be resolved despite everyone's best efforts, a change may be required.

Children with disabilities and their families have people who will come and go over their lifetime. Sometimes Aides or caregivers move on to new jobs, retire or change for reasons such as health, moves or returning to school for post-secondary education. Families learn to adjust, but when you have an Aide or caregiver who really fits well with your child, it is hard to see her go. It is important however to recognize that although these changes occur, the child maintains a sense of stability within the family.

5

Module 5: Working with your Child's School

Unit 1: Working Positively with your Child's School Team

- Topic 1:** Parents as partners in education
- Topic 2:** Sharing strengths, needs & strategies
- Topic 3:** Get to know your child's teachers & school community
- Topic 4:** Communicating positively with your child's teacher & educational staff
- Topic 5:** Communicating respectfully during conflict
- Topic 6:** Key points

Unit 2: Helping Your Child Get Ready for School

- Topic 1:** Guidelines for helping your child get ready for school
- Topic 2:** Positive examples
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Unit 3: Managing Homework

- Topic 1:** Managing homework/FASD
- Topic 2:** Structure, routine & reinforcement
- Topic 3:** Helping your child with his homework
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Unit 4: Preparing Your Child for Transition

- Topic 1:** Preparing your child for transition
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- Topic 3:** Dealing with transitions between grades, schools & work
- Topic 4:** Transitions during family change
- Topic 5:** Key points

Unit 5: Resolving Conflict

Topic 1: Parents' rights & responsibilities

Topic 2: What do I do if I think there is a problem at school?

Topic 3: What if I can't resolve the problem at the school level?

Topic 4: Key points



Unit 6: Bullying

Topic 1: Bullying

Topic 2: How can I tell if my child is being bullied?

Topic 3: What can I do if my child is being bullied?

Topic 4: How can I tell if my child is bullying others?

Topic 5: What can I do if my child is bullying others?

Topic 6: What if my child is a witness of bullying?

Topic 7: What can I do about cyberbullying?

Topic 8: Key points

Unit 1

Working Positively with your Child's School Team

“When parents, teachers, students and others view one another as partners in education, a caring community forms around students ...” – Epstein et al. 2002

Parents as Partners in Education

As parents, you play an important role in making sure that your child has a successful school experience. Working with your child's educational staff in a positive and productive way is the key to helping children and youth with Fetal Alcohol Spectrum Disorder (FASD) to be successful in school and in life. Positive relationships also help increase a sense of well being within adults caring for children and provide a circle of caring and support that benefits everyone. Building relationships based on trust, knowledge and common goals takes time, effort and commitment but makes an enormous positive impact on all those involved.

Research shows that parental involvement results in higher student achievement and safer school environments. Studies also show that for students who are at-risk such as children and youth with FASD, parent and family involvement is the single most important determinant of success in school. Parents and caregivers can play an important role in their child's success throughout their school career through the sharing of information, support and working together with all those involved with their children.

Sharing Strengths, Needs and Strategies

Parents and caregivers can contribute important information about their children with FASD by sharing the strengths and needs of their children as well as strategies that work at home. Many of these strategies can be successfully adapted for use in the classroom and throughout different school environments. Working positively with your child's school team can help teachers plan programming and choose materials and tasks that will be more motivating, engaging and meaningful to your children.

Children and youth themselves can be a great resource for identifying their own strengths and interests. They can often point out things that adults have not thought of. To be most effective, strategies must be aligned with each individual child's needs and must be respectful, manageable and compatible with the student's learning preferences, strengths and developmental level.

Information that may be beneficial for you to share with your child's teacher and educational staff could include the following:

- relevant medical information including any medications, diagnoses, etc.
- successful learning and behaviour techniques that you are using at home. Both things that work well and things that don't work can be very helpful to school staff
- changes in the home setting – such as a death, divorce, unemployment or loss of a pet that might cause emotional reactions
- your child's past school and/or life experiences
- ongoing goals for your child that you are supporting at home
- previous assessments or testing information
- community supports that you may be accessing
- your own hopes, dreams and wishes for your child's school experience

Get to know your child's teacher and school community

Getting to know your child's teacher and other educational staff is an important step in developing a positive and trusting relationship. This helps to set the foundation for future positive communication.

Strategies that many parents have found helpful include:

- Visiting your child's school throughout the school year. At the beginning of the year ask the teacher how to make arrangements to visit the classroom.
- Make sure to meet with the teacher and other appropriate staff to share any helpful advice and information about your child.
- Consider volunteering at the school if only a few times per year.
- Join the parent advisory group at the school and help provide input into school policies, procedures and other school activities.
- Read the school newsletters, as they often contain valuable information that concerns your child.
- Become familiar with the school's policies and procedures about attendance, discipline and other issues.
- Go to all parent-child-teacher conferences. Don't be afraid to ask questions.
- Keep all school information in one place so it's handy for meetings at the school or when seeing others in the community about your child.

Communicating positively with your child's teacher and educational staff

- Talk with your child's teacher and agree on how you will communicate, including best ways and times that the teacher can contact you and vice versa. For example, you may decide to set up a daily communication book that can go back and forth with your child.
- Tell the teacher how you may be contacted if you don't have a phone, are working or may be hard to reach. Include alternate contact information if possible.
- Make an appointment with the teacher to discuss any specific concerns. Make arrangements to telephone, text, and email or write a letter if you are unable to meet.
- Ask that the teacher, principal, liaison worker or school counsellor meet with you in your home if you would feel more comfortable meeting there.
- Take time to celebrate your child's successes and ask the teacher to let you know when things are going well as well as when your child is having difficulty.

- Take time to show appreciation to your child's teacher and staff for all that they do to help your child succeed. Even a note of appreciation can help to build a trusting, caring and open relationship.
- Understand that communication and collaboration take time. You may be invited to participate in a variety of meetings over the course of the school year. These may include in-school team meetings as well as consultations with other support personnel, in addition to regular parent-teacher conferences.
- Give change a chance. Change takes time. Your child may require a period of adjustment to a new setting before positive change is evident. Clear, open communication among all team members will go a long way to ensuring expectations are reasonable.

Communicating respectfully during conflict

- Work cooperatively. Listen to and consider the perspectives of others. Most of the people you negotiate with have good intentions, even if their opinions may differ from yours.
- Concentrate on concerns, not emotions. Find areas where you agree and build on those.
- Expect courtesy and respect from school staff. Meaningful parent involvement is a core value of the education system.
- Be respectful of those who are working on behalf of your child. Go out of your way to be polite and diplomatic and always keep your child's needs in the forefront of the discussion.
- Be patient and persistent. Change may happen slowly; finding the information or assistance you require may be a time-consuming process of trial and error. Keep moving toward your goals step-by-step.
- Be a good communicator. The old adage "it's not what you say but how you say it" is so true when working with others. Clear and regular communication among all members is key to the success of your child's school team.
- Ask for clarification if there is anything you are unsure of. You may hear terms you are not familiar with, such as IPPs (individualized program plans) or outcomes. If at any time you are unsure about specific information, ask. To communicate effectively, everyone on the team must speak and understand the same language.

- Enlist the support of like-minded parents, teachers, administrators and community members. The best advocates work with others. By working in collaboration with teachers and other parents, seeking family support and accessing assistance through community agencies, you can create win-win solutions that work for everyone.
- Recognize and cherish the accomplishments of the team. Celebrate the positive impact they have on your child's learning, and emotional and social life.

Key Points

1. Research shows that parental involvement results in higher student achievement and safer school environments.
2. Studies also show that for students who are at-risk such as children and youth with FASD parent and family involvement is the single most important determinant of success in school.
3. Information beneficial for you to share with your child's teacher and educational staff could include:
 - relevant medical information including any medications, diagnoses, etc.
 - successful learning and behaviour techniques that you are using at home. Both things that work well and things that don't work can be very helpful to school staff.
 - changes in the home setting – such as a death, divorce, unemployment or loss of a pet that might cause emotional reactions
 - your child's past school and/or life experiences
 - ongoing goals for your child that you are supporting at home
 - previous assessments or testing information
 - community supports that you may be accessing
 - your own hopes, dreams and wishes for your child's school experience
4. Getting to know your child's teacher and other educational staff is an important step in developing a positive and trusting relationship.
5. Communicate positively with your child's school team and understand that communication and collaboration take time.
6. Treat each other with respect even during times of conflict and change.
7. Recognize and cherish the accomplishments of the team. Celebrate the positive impact they have on your child's learning, and emotional and social life.

Food for Thought

Reflect on following questions to consider how you can work effectively and positively with your child's teacher and school staff.

- 1. What information should I share with my child's teacher and team?**
- 2. Am I missing any information that I should have? If so, where can I get it and who should have it?**
- 3. Do I know who my child's team members are and what they do? Who should I contact if I have a problem?**
- 4. How do I communicate with my child's teacher? Is it working for me and my child? If not, what are some other ideas that I can suggest?**
- 5. How can I support my child's teacher and team? What support do I need?**
- 6. How would my child like to celebrate his or her successes? How can I help to make that happen?**

References and Resources:

Our Words, Our Ways: Teaching First Nations, Métis and Inuit Learners <http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

Re: Defining Success - A Team Approach to Supporting Students with FASD (2009) <http://education.alberta.ca/admin/special/resources/re-defining.aspx>

The Learning Team – A Handbook for Parents of Children with Special Needs, 2003 <http://education.alberta.ca/admin/special/resources/learningteam.aspx>

Unit 2

Helping Your Child Get Ready for School

“Getting ready for school each day was a challenge with my child. I would end up raising my voice and she would end up in tears. Once we began a consistent routine with pictures that she could follow, everything became so much easier.

I realize now that she just couldn’t remember what she was supposed to do when she got up and didn’t understand why I was impatient with her. Now our mornings run much more smoothly and if she forgets to do something I simply remind her. We’re all much happier!”

Guidelines for Helping Your Child Get Ready for School

Getting your children ready for school each day can be a challenge for many parents. If your child has Fetal Alcohol Spectrum Disorder (FASD) you may feel even more challenged. A positive start to the school day can help contribute to a sense of security, self-confidence and increased learning. Getting enough sleep, waking up to an established routine, eating a good breakfast and getting off to school on time helps your child to start their school day in a positive manner.

In general, children, youth and adults

with FASD benefit from consistent, unwavering structure. A typical person will adapt to various environments and understand what is expected in different situations. People with FASD will not adapt as easily and are less able to generate their own structure. It will be easier for children with FASD to learn and behave when the guidelines for learning and behaviour are made clear and visible. When the structure changes or is withdrawn, the child’s learning and behaviour will suffer. Having a routine that is followed every day can

help your FASD child to learn and remember what to do and helps to provide them with a feeling of security.

Providing positive, caring and specific reinforcement to your child will also help your child to learn what is expected of him and can help to alleviate some challenging behaviours. Remember that each child is unique and your

child, depending on his strengths and needs, may require you to repeat directions, remind him what he is supposed to do frequently and may also need you to redirect his focus back to his task. Some children may require a little help; some may need constant supervision and assistance.

Guidelines for helping your child get ready for school:

- ▶ Provide structure, routine and positive reinforcement to help your child get ready for school each day. Always follow the same steps for daily routines and use visual or written aids to help your child remember what to do.
- ▶ Keep your home environment as calm and quiet as possible. Children with FASD are often extremely sensitive to lights, sounds or touch and may become very anxious if their senses are overwhelmed.
- ▶ Break each routine down into manageable steps for your child. If you give your child too many steps to do all at once she will likely not remember, thus causing her and you anxiety and frustration. Determine how many steps your child can handle and plan accordingly.
- ▶ Don't assume that your child will remember the routine day to day. Many children with FASD have difficulty remembering from day to day. They may also have difficulty transferring their learning from one situation to another. For example, getting dressed in the morning for school may be a routine that your child is comfortable with at home but he or she may not be able to do it at Grandma's house.
- ▶ Don't assume that your child understands what he or she is able to do even if they can repeat the steps back to you. Children with FASD may be able to repeat what you want them to do but may not be able to understand what you want them to do. You may need to help your child by showing them the steps needed.
- ▶ Be very clear when you are teaching your child how to do something. Children with FASD have difficulty thinking abstractly or generalizing from one situation to the next. They need to be told exactly how to do something and then praised for doing it correctly.
- ▶ Be as organized as possible. Lay out clothes for school the night before so that your child knows what to put on and in what order. Recognize that even small changes, such as putting the clothes on a chair instead of on the dresser where they are usually put can cause your child to not be able to follow the usual routine.

- ▶ Know how to recognize that your child is getting anxious, frustrated or upset. Look for cues that alert you to your child feeling overwhelmed. Some children may become quiet and withdrawn; others may act out when they don't understand.
- ▶ Look for what your child is doing right and let them know through praise. It can be frustrating at times to have to repeat instructions and go at a slower pace for your child, especially during a busy time such as getting ready in the morning. Take your time, celebrate your child's achievements and focus on what your child is doing right, not what they are doing wrong.
- ▶ Plan ahead for changes in routine as much as possible. Help your child plan for any changes in routine such as a friend picking him up at school rather than yourself. Let him know that this will be happening, give him a picture reminder in his steps to do at the end of the day and ask your child's teacher to remind him at the end of the school day.
- ▶ Be patient and remember that your child is developmentally younger than her age. Children with FASD may need to have things repeated over and over as they are learning new routines, where other children may only need a few reminders. Patience, structure, routine and praise will help them to learn in a positive environment.

Positive Example

Amina is an 8 year old child with FASD. She has trouble remembering what day it is and what she needs to do when she wakes up in the morning and gets very anxious when she doesn't know what is going to happen. To help her, her parents remind her each night when they tuck her in bed what the next day is and what her first step is when she gets up. This helps to relieve her anxiety and she can go to sleep.

They have also posted a visual on the wall by Amina's bed with a picture of each day of the week and the steps that she needs to complete when she gets up. In addition, they lay her clothes out in the same place each day so she knows where they are.

When they wake her up in the morning they say, "Good morning, Amina. It's Tuesday morning and time to get up and put

on your clothes." They point to the chart on the wall to help her remember what she is to do and praise her when she puts her clothes on. "Good for you, Amina! You got dressed all by yourself!" If she needs help remembering what to do next, they gently guide her by pointing to her chart or helping to guide her to what is next. They follow those same steps reminding Amina what she is to do next if she needs help and then praising her when she follows through. Prior to her leaving home to catch the bus, they review the bus rules with her and remind her what to do when she gets to school (e.g. say goodbye to the bus driver and go to her classroom). On days when Amina appears anxious and uncertain they provide her with extra help and reassurance.

Amina's parents also work with her bus driver, her teaching staff and her siblings

to teach them how to help her when she needs it. They stay in touch on a daily basis with her bus driver by walking her to the bus each day and will continue to do so until Amina and her siblings become familiar with her routine.

Amina's parents have found that the structure that they provide not only helps her but helps her siblings as well. The morning

and after school routine prove to be a positive way to help keep a busy schedule calm and orderly. In addition, Amina's parents have found that looking for what all of their children are doing correctly and praising all of them has encouraged and supported positive habits and behaviour in everyone.

Key Points

1. It is easier for children with FASD to learn and behave when the guidelines for learning and behaviour are made clear and visible.
2. Providing positive, caring and specific reinforcement to your child will help your child to learn what is expected of him and can help to alleviate some challenging behaviours.
3. Guidelines for helping your child get ready for school include:
 - Provide structure, routine and positive reinforcement to help your child get ready for school each day.
 - Keep your home environment as calm and quiet as possible.
 - Break each routine down into manageable steps for your child.
 - Don't assume that your child will remember from the routine from day to day.
 - Don't assume that your child understands what he or she is able to do even if they can repeat the steps back to you.
 - Be very clear when you are teaching your child how to do something.
 - Be as organized as possible.
 - Know how to recognize that your child is getting anxious, frustrated or upset. Look for what your child is doing right and let them know through praise.
 - Plan ahead for changes in routine as much as possible.
 - Be patient and remember that your child is developmentally younger than his or her age.

Food for Thought

Reflect on the example of Amina's morning routine. Most families struggle with getting children ready in the morning, whether or not they have a child with a disability. Use the following questions as a guide to come up with a plan that may help your morning go more smoothly.

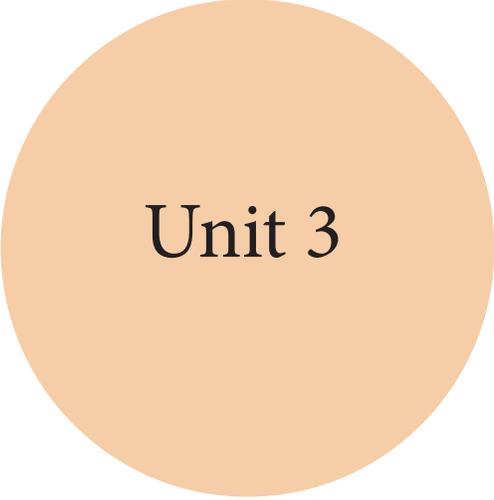
- 1. Does my child have trouble getting ready for school in the morning? How do I react when she has difficulty? What could I do differently?**
- 2. What structure have we put in place to help my child? What does he need? Do simple reminders help or would it be helpful to have pictures or words to help him remember?**
- 3. Is our routine helping her to become more independent? Is she able to be more independent? How can I work towards that goal?**
- 4. Am I doing anything to encourage negative behaviour such as paying too much attention to him when he refuses to eat breakfast every day? How can I turn that around so that he will eat his breakfast without arguing and how can I reward him for that?**
- 5. What kinds of positive praise can I say to my child when she's doing well?**
- 6. How can I help her to have a good ride on the bus? Can I set up something with her bus driver to help?**
- 7. What questions or information do I have that I can share with his teacher to make the transition to school each day a positive one?**

References and Resources:

FASD Support Site – Fetal Alcohol Spectrum Disorders – Bright Tomorrows http://fasd.bright-tomorrow.com/index.asp?page=3_1_1

Re: Defining Success a team approach to supporting students with FASD <http://education.alberta.ca/media/932765/redefining-action6.pdf>

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope (2004) <http://education.alberta.ca/admin/special/resources/fasd.aspx>



Unit 3

Managing Homework

“It was frustrating for me trying to do homework. By the time I sat down to do it, I had forgotten the steps the teacher taught me at school. My parents would try and show me the steps but they were different steps from what the teacher used. I did not understand what my parents were saying and I would become angry and frustrated. I could do it fine at school earlier in the day but now at home, I could not. It was like I was right there but couldn’t reach it.”

Myles Himmelreich, a young man impacted by FASD

Managing Homework/FASD

Homework can be a challenge for many families of students with FASD. However, with structure, routine, positive reinforcement and support children with FASD can and do experience success with their homework. Parents and caregivers of children with FASD know their children better than anyone and

can work with educators to come up with strategies that will help their children to be successful in school and with their homework. Other children in the family can also benefit from many of the same strategies as their siblings with FASD.

A few things to remember about FASD...

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella label that is currently used throughout North America to refer to a variety of physical changes, and neurological and/or psychometric patterns of brain damage associated with fetal exposure to alcohol during pregnancy. It provides a way to describe the continuum of deficits and challenges that individuals may have by being exposed to alcohol during pregnancy.

The majority of children who have learning, behavioural and functional difficulties as a result of prenatal exposure to alcohol have an “invisible disability” which may make it hard to diagnose. They may have problems with memory, attention, and comprehension.

Structure, Routine and Reinforcement

In general, children, youth and adults with FASD benefit from consistent, unwavering structure. A typical person will adapt to various environments and understand what is expected in different situations. People with FASD will not adapt as easily and are less able to generate their own structure. It will be easier for children with FASD to learn and behave when the guidelines for learning and behaviour are made clear and visible. When the structure changes or is withdrawn, the child’s learning and behaviour will suffer. Having a routine that is followed every day can help your FASD child to learn and remember what to do and helps to provide them with a feeling of security.

Providing positive, caring and specific reinforcement to your child will help her to learn what is expected and can help to alleviate some challenging behaviours. Remember that each child is unique and your child, depending on their strengths and needs, may require you to repeat directions, remind them what they are supposed to do frequently and may also need you to redirect their focus back to their task. Some children may require a little help; some may need constant supervision and assistance.

Helping your child with his homework

Parents and caregivers can work with their child’s educational staff to come up with some ways to help their child to complete his homework. Communicating what works at home and at school can help parents and educators to develop consistent expectations

and techniques, thus increasing the chances that the child will succeed. Since every child is unique, the amount and time set aside each day for homework will likely vary and may change over time as the needs of the family changes.

Some general guidelines for strategies that parents and caregivers can use to promote positive experiences with homework include:

- Provide a quiet workspace for the child away from noise and stimulation. This may be the kitchen table with all the children in the house sitting down to do their homework at the same time or another quiet space in the house. Having needed materials such as pencils, pens and paper available helps to reduce the number of distractions that looking for those materials can create. Some children may need ‘white noise’ to help them focus such as a radio turned low to quiet music. The important thing is to look at what works for your child and her needs.
- Set up a regular time for homework or develop a weekly homework schedule. Building homework time into the daily routine can help to provide the structure and consistency that your child needs. Posting the schedule and steps to follow for doing homework in a place that is seen easily by the child helps to provide prompts to remember what to do and when. Many children also benefit from pictures that help them to know what to do. For instance, children may come home from school, get a snack and then sit down at the table ready to begin their homework. Having the same schedule for all of your children benefits all of them and can reinforce positive home work behaviour.
- Use a communication book, or an agreed upon strategy, to stay in daily contact with your child’s teacher(s). A daily communication book that the child can bring back and forth to school can help parents and educators to keep in touch, thus providing consistency and communication between home and school. Homework assignments and how they should be completed can be recorded in the communication book and reviewed with the child prior to starting their homework. Some parents and teachers like to use email, the phone, texting or another form of communication that both are comfortable with and that works for them.
- Review the homework assignment(s) with your child and the steps that he is to follow. Many children with FASD need help in getting started and staying on task. Parents can then assist their children in planning the tasks that need to be completed. Often, breaking down assignments into small, manageable chunks is most helpful and prevents the child from becoming overwhelmed. If your child is easily distracted it might be helpful to cover up the other problems or homework so that he can focus on one thing at a time and experience success before moving on to the next item.
- Use this time to build a positive, supportive relationship with your child. Homework time can be a chance to work cooperatively with your child with FASD and the other children in your household. It provides a chance to look for things that the child has done correctly and give positive feedback (e.g. “Good for you, Jimmy! You finished your first math problem and it’s correct!”) Positive feedback that is specific, enthusiastic and given warmly encourages your child to keep working and helps them to develop increased self-confidence. Reinforcing your other children has the same effect and can

enhance family relationships in a positive way. Be sure not to give attention to misbehaviour as this can send the message that “if I act out, I can get your attention” or “if I act out I won’t have to do this math problem”. Instead, gently and quietly redirect your child back to his task and reinforce him for getting back to work. Schedule breaks or reward partially completed tasks with a break if appropriate.

➤ If homework becomes an ongoing issue, talk to the teacher about alternate solutions. Let the teacher know if the homework is too confusing or difficult for the child to do or if it is taking too long. A general rule of thumb is a maximum of 10 minutes per grade; e.g., Grade 3 student, no more than 30 minutes, including short breaks every 15 minutes or so. For some children, the best solution might be no homework if it causes undue stress and tension. You may also want to work with the teacher to help your child to develop a “circle of support” – a group of peers who they can call if they need help with homework.

➤ Work with the teacher(s) to come up with strategies that work with your child.

Teachers may want to try these some of the strategies listed below:

- Teach children how to use daily planners. Provide a visual system to record and monitor what tasks need to be done, and check off completed items,
- Display simple, numbered, concise steps for completing assignments. Use pictures to accompany written and verbal instructions, whenever possible.
- Give students photocopies of instructions for multiple-step assignments. Number the steps or separate them into a stapled instruction booklet to further emphasize the order and steps in the process. When possible, provide a finished sample.
- When appropriate, reduce the workload so it can be accomplished within a reasonable time.
- Encourage students to put question marks beside any homework that they don’t understand. This reminds them to ask for clarification at the end of the lesson.
- Encourage students to teach new information to another person. Try having them teach you or one of their siblings.

Teach Test taking Skills

The following are some specific strategies for Teaching test taking skills.

Through Discussion and brainstorming, generate a list of tips for taking tests, such as the following:

- Read all directions TWICE.
- Highlight key words
- Pay special attention to words in bold or italics
- Read all the important clues in charts, pictures, graphs and maps
- When you are given information for more than one question, reread the information before answering each question.
- If there is a word that can't read or don't understand, read around it and ask, "What word would make the most sense here?"
- Mark any questions you find difficult, skip them and come back to them at the end of the test.
- Often, test questions have more than one step and ask you to consider a number of pieces of information. On a scrap paper, jot down notes for each step of the problem. Use this information to find your answer.
- Talk through your plan in your head. "First I have to find out ... then, I take that number and ... find out ... I need to ..."
- Use smart guessing strategies. Do not leave any questions unanswered.



- Keep working. If you finish early, read through each question and answer to make sure you have a complete answer.

Teach Your Child Techniques for Managing Test Anxiety

Samples of specific strategies to teach your child techniques for managing test anxiety are as follows:

- Identify what stress looks like and feels like, specifically when writing tests.
- Rehearse simple steps for managing anxiety, such as:
 - Close your eyes
 - Breathe deeply and slowly
 - Relax your hands.
- Have your child make a tip card outlining a strategy for handling test anxiety.
- If necessary, refer to appropriate resources. At times, your child may need professional counseling or medical intervention to deal with anxiety issues.

Key Points

1. Children with FASD need structure, routine, positive reinforcement and support to experience success with their homework.
2. Provide a quiet workspace for the child away from noise and stimulation.
3. Set up a regular time for homework or develop a weekly homework schedule.
4. Use a communication book, or an agreed upon strategy, to stay in daily contact with your child's teacher(s).
5. Review the homework assignment(s) with your child and the steps that they are to follow.
6. Use this time to build a positive, supportive relationship with your child.
7. If homework becomes an ongoing issue, talk to the teacher about alternate solutions.

Food for Thought

- 1. Do I have a consistent structure in place for helping my child deal with homework? Can I improve what I am doing to help him be more successful?**
- 2. Do I have a way of communicating with my child's teacher that is working well for me? If not, what suggestions might I have for improving how we communicate?**
- 3. Do I reinforce and recognize my child's efforts in a positive way? What can I do and say to praise him when he does well?**
- 4. Am I giving my child any attention for negative behaviours? If so, what can I do differently so that I can get him back on task without giving him lots of attention for negative behaviour?**
- 5. How often does my child need a break? How long should she be working at her homework?**
- 6. Is our homework structure working for the other children in our home? What could we do to make it a positive experience for everyone?**
- 7. What questions do I have for my child's teacher(s) regarding homework?**

References and Resources:

The Learning Team - A Handbook for Parents of Children with Special Needs, 2003 <http://education.alberta.ca/admin/special/resources/learningteam.asp>

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope (2004) <http://education.alberta.ca/admin/special/resources/fasd.aspx>

Unit 4

Preparing Your Child for Transition

Involve children and youth in every step of the transition planning process. Transition plans are for young people, about young people and are developed with the involvement of young people.

Introduction

A transition is any event that results in changes to relationships, routines, expectations or roles. Transitions are a normal part of life and occur throughout everyone's life. Starting school, moving from grade to grade and changing schools are common transitions for children.

While any student can have difficulty with transitions, students with Fetal Alcohol Spectrum Disorder (FASD) may have greater difficulty coping with transitions. To minimize these difficulties, thoughtful transition planning is important.

Parents and caregivers have a crucial role in ensuring successful transitions in children and youth with FASD. They can help to make transitions run smoothly by having positive expectations, reviewing what will happen with their children ahead of time, keeping track of records and planning documents and

providing needed support during transition times. Developing a positive approach to all transitions, whether they are daily transitions such as getting on and off the bus or transitions to another grade, school or home, can help children to feel more secure and comfortable with knowing how to deal with change.

Transition planning should focus not only on the academic skills needed for success, but also on helping children develop the ability to problem solve in new situations, monitor and regulate their own performance, and interact appropriately with peers and authority figures. By working together parents, children, family, educators, community members and others can share their knowledge resulting in informed decision making, the acceptance of joint responsibility and a generous circle of support for the child throughout their life.

Dealing with Daily Transitions

Parents can help their children with FASD to deal effectively with the transition times that make up their daily life. Common transition times include waking up in the morning, getting dressed, eating breakfast, getting on the bus, getting off the bus at school, doing homework and going to bed.

Strategies to help with daily transitions can include:

- Developing a consistent routine for each day and each activity
- Putting up visual and/or written reminders of what to do for each activity
- Gentle reminders, encouragement and physical prompts (e.g. Holding up a sock to remind your child what comes next when getting dressed)
- Positive reinforcement for completing steps independently or trying to complete them (e.g. “Good job putting your socks on Connor! Now let’s see you put your shoes on!”)
- Reviewing the steps each day or as often as necessary to help your child be successful.

Dealing with Transitions between grades, schools and work

Transition planning decisions need to be based on an understanding of the individual child. It involves identifying the kinds of skills that need to be in place for your child to be successful in future placements and settings, and developing a plan of action to ensure they acquire the needed skills and attitudes. This means understanding the child’s strengths, needs and goals, as well as those of your family.

Transition planning is dynamic and ongoing and should involve your child, you as parents and caregivers, school staff, community service providers and any others important

in your child’s life. It can include specific plans for moving between education placements, programs, schools, work, post-secondary training and towards increased independence as an adult.

It may be helpful to practice what will happen with your child at each transition stage prior to her actually experiencing it. For example, going on a bus ride and visiting the new school with your child before she rides the bus to school for the first time may help her feel more comfortable. Sample strategies to help manage transitions during key times in your child’s life include:

► The Early Years

- Seek opportunities to participate in parent support groups. This helps to create a social network for both you and your child early on.
- Involve children early on in recreational activities to help develop social, physical and cognitive skills, all which help foster early childhood development.
- Help your child or youth build communication skills so he or she can develop relationships effectively.
- Emphasize the positive and recognize your child's strengths. This will give him or her confidence and help your child to feel that he or she has lots to offer.
- Support your child in taking pride in his or her culture, ethnicity or religion. By taking pride in these important aspects of their identity, children strengthen identities and develop relationships with other children who share common values.

► Transitioning into School

- Let education staff know that you, as a parent or caregiver, want to be a partner in your child's education. Share information with your child's teacher and school team about FASD and your child's specific strengths and needs.
- Communicate frequently with your child's teacher(s) and support your child in learning activities such as reading to him and helping with homework at home.
- Keep in touch with teachers regarding your child's progress, including both challenges and successes. Work with your child's education team to coordinate strategies and routines so that they are similar, consistent and predictable for your child.
- Provide reassurance to your child about aspects of her life that will not change following the school transition, as stability helps make for a smooth transition.
- Make sure your child gets enough rest by going to bed early on school nights. Wake your child up early enough to eat a good breakfast and be prepared for the day. Children's physical needs must be met before they are ready to learn.
- Prepare your child not only for the start of the day, but also for dismissal from school at the end of the day. Dismissal can be a scary and hectic experience for children who are not supported and prepared for this busy time.
- Talk with your child and encourage him to share his feelings and experiences regarding school. Help him come up with strategies to deal with situations that he don't understand and reassure him that you are there to help him.

➤ **Transitioning from Elementary School to Junior High School**

- Attend, with your child or youth, any scheduled open houses, orientations or welcome days that schools may offer.
- Stress that your child or youth is not alone in social challenges such as peer pressure and making new friends. Placing your child in a variety of social situations in the school, community, and neighbourhood can assist in the development of a variety of social skills.
- Work with school professionals to make your child or youth feel connected while attending school. A sense of connectedness can help reduce high-risk behaviour and the possibility of dropping out of school.
- Listen and talk with your child. During adolescence, youth want and need to share their feelings to help cope and become more aware of their changing identity.
- Help children and youth anticipate possible challenges and help them come up with coping strategies if these challenges are faced.
- Encourage increased independence. Work with your child's school and support team to determine developmentally appropriate actions to help them gain greater independence.

➤ **Transitioning into High School and into Adulthood**

- Ask children and youth about their ambitions and goals and create long-term goals with youth to help direct them along the path to adulthood. Having a goal to work towards helps to focus and motivate youth.
- Place a high value on continued education, especially in high school, as this support has been closely linked to participation of youth in school.
- Encourage youth to prepare for the work force by helping them develop a variety of skills and interests.
- Ensure that your youth learns how to follow directions, be on time, work with a team and problem solve within the context of his unique needs. Developing strong work habits is critical to maintaining a job.
- Work with the multidisciplinary team and your child's worksite employer, if appropriate, to help them understand FASD and the specific needs and accommodations that your child may require.

- Create opportunities for youth to become involved in their community. Assisting youth in developing skills and creating a sense of empowerment is made easier through community involvement and can help provide networking opportunities.
- Consider the following key issues as your youth with FASD transitions into adulthood and becomes independent: transportation, financial management, housing options, relationships, education, employment, personal care and decision-making skills.

Transitions during Family Change

Changes in the family can be especially traumatic for all children and youth, including those with FASD. Parents and caregivers may find this a challenging time as they, too, are dealing with their own feelings of loss, grief and change. Despite that, there are a number of strategies that can help parents to help their children as well as themselves.

- Emphasize that your child or youth's basic needs will be taken care of during this time of change. This will help to lessen your child or youth's anxiety.
- When your child is moving to a new school or program, consider contacting the school in advance to provide the staff with relevant information about your child. Arrange for a visit, if possible, to familiarize your child with the school building, bus stops, school routines and the adults within the school setting.
- Reassure your child or youth that it is normal for her to have many different feelings and emotions about all of the changes that accompany a separation or divorce. Some of the emotions that children and youth may express include anxiety, stress, sadness, relief or confusion.
- Avoid putting your child or youth in the middle of a divorce or separation by communicating effectively with all members of the family.
- Encourage your child or youth to express himself during his time of loss. Sharing memories, listening to feelings, and helping your child engage in everyday activities can be a helpful reminder that he is not alone.
- Enlist the support of friends, other family members and your child's school team to help you as you deal with these changes yourself. Letting the school know that your child may have difficulty for a period of time allows them to help provide extra support for you and your child.

Key Points

1. Parents can help to make transitions run smoothly by having positive expectations, reviewing what will happen with their children ahead of time and providing needed support during transition times.
2. Transition planning involves identifying the kinds of skills that need to be in place for your child to be successful in future placements and settings, and developing a plan of action to ensure they acquire the needed skills and attitudes.
3. Strategies to help with daily transitions can include:
 - Developing a consistent routine for each day and each activity
 - Putting up visual and/or written reminders of what to do for each activity
 - Gentle reminders, encouragement and physical prompts (e.g. Holding up a sock to remind your child what comes next when getting dressed)
 - Positive reinforcement for completing steps independently or trying to complete them (e.g. “Good job putting your socks on Connor! Now let’s see you put your shoes on!”)
 - Reviewing the steps each day or as often as necessary to help your child be successful.
4. Work with your child’s education team to coordinate strategies and routines so that they are similar, consistent and predictable for your child.
5. Work with school professionals to make your child or youth feel connected while attending school. A sense of connectedness can help reduce high-risk behaviour and the possibility of dropping out of school.
6. Encourage increased independence. Work with your child’s school and support team to determine developmentally appropriate actions to help them gain greater independence.
7. Ask children and youth about their ambitions and goals and create long-term goals with youth to help direct them along the path to adulthood. Having a goal to work towards helps to focus and motivate youth.
8. Emphasize the positive and recognize your child’s strengths. This will give him confidence and help your child to feel that he has lots to offer.

Food for Thought

Reflect on the types of transitions facing your child. The following questions may help you consider how to address them effectively.

- 1. What are we doing that is working each day to help our child get ready for school? What isn't working?**
- 2. What strategies can I try to help my child be successful in his routine each day?**
 - a. What transitions is my child facing in the near future?**
 - b. How can I help my child best deal with these transitions?**
 - c. Do I know what my child's hopes and dreams are for the future? How can I talk with her about this?**
- 4. What are my child's gifts and talents? Have I communicated these to his teacher and talked with him about these?**
- 5. Is there a long term plan in place for my child? Who do I need to talk with about that?**

References and Resources:

Building on Success: Helping students make transitions from year to year <http://education.alberta.ca/media/352661/build.pdf>

Re: Defining Success - A Team Approach to Supporting Students with FASD (2009) <http://education.alberta.ca/admin/special/resources/re-defining.aspx>

Guidelines for Supporting Successful Transitions for Children and Youth
Children and Youth in Transition: An Alberta Children and Youth Initiative
http://www.child.gov.ab.ca/home/documents/youthprograms/Guidelines_for_Supporting_Successful_Transitions_for_Children_and_Youth.pdf

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope (2004) <http://education.alberta.ca/admin/special/resources/fasd.aspx>

A Handbook for Parents of Children Who Are Gifted and Talented, 2004 <http://education.alberta.ca/admin/special/resources/journey.aspx>



Unit 5

Resolving Conflicts

” My son just started school this year. Only a few weeks went by when the school contacted us and asked us to come in to talk with them about our son. My husband and I were so angry when we heard that he was having trouble in the classroom! After all, he had only been there a few weeks! But, we worked with his teacher and school team and now he’s getting the help that he needs. They’ve helped us to get him tested and we’re trying some new routines at home. Things seem to be going well for him now. I’m glad that we took the time to work with the school team. I feel that he’s getting the help that he needs and things are even running more smoothly at home.”

Parents Rights and Responsibilities

Parents have a right and a responsibility to participate in decisions about the education of their children. Although all children rely on their parents to ensure they have an appropriate programming and school placement, children with special needs, including Fetal Alcohol Spectrum Disorder (FASD), have a greater dependence on adult involvement.

Some parents may not be comfortable dealing with conflict. This may be particularly true in Aboriginal communities where parents

may hold a more traditional view of non-interference with the school, wishing to defer to the professionals with regards to their children.

Most parents, including those with FASD children, also have their own personal histories with schools and may not feel comfortable approaching their child’s teachers and the school. Parents may wish to involve others, such as family members, Elders or trusted friends to help them to advocate for their child.

What do I do if I think there is a problem at school?

Talking to children about experiences and observing their behaviour toward school are keys to ensuring that they are on the right track. If your child is excited about learning, talks openly about his or her classes, and is eager to go to school, he or she is most likely being appropriately challenged and supported.

If you feel your child may not be receiving the right programming, or you have any other concerns, talk to your child's teacher. Always try to resolve issues with the people who are working with your child. This means meeting with your child's learning team and looking for solutions that work for everyone, especially your child.

School boards are required to make every reasonable effort at the school and district level to resolve concerns collaboratively with parents. As well, each Reserve school has its own policy in place—although policies may differ from one federally run school to the next. Despite these efforts, there may be differences of opinion about the education of children with FASD between parents (or in some cases, an older student) and the school. When this happens, there are a number of strategies for successfully resolving these differences.

How do I resolve conflict at the school level?

Consider the following when trying to deal with a challenging situation or conflict:

- ▶ Begin by requesting a meeting with your child's teachers. Indicate what the topic will be. This information allows teachers to schedule an appropriate amount of time, and be better prepared to answer your questions and address particular concerns. Bring a family member, Elder or friend to the meeting if you will feel more comfortable.
- ▶ Be prepared. Write down questions and concerns you want to address. It can help you to remember all of your questions and concerns, which is sometimes hard to do when you are upset and/or dealing with conflict.
- ▶ Take time to consider what you would like the outcome of the meeting to be. This will help you focus your discussion and problem solving.
- ▶ Focus your concerns on your child's learning needs. Decide what is most important and focus your energy on that.
- ▶ Be prepared to consider and share possible solutions. Working together can sometimes generate solutions that might not be readily apparent to the parent, child or teacher.

- If possible, involve your child in finding a solution. Children and youth who participate in finding a solution to their problems will often commit more effort to resolving the problem.
- Ask as many questions as needed to ensure you have a clear understanding of your child's progress and programming.
- Take notes, especially with respect to recommendations and timelines. Confirm those commitments both verbally at the end of the meeting and through a follow-up letter or form of communication that is agreed upon at the meeting.
- If you feel that additional information is necessary, schedule another conference at the conclusion of your meeting.
- Give teachers and the school time to implement changes. If you come to an agreement that a certain change will be made, establish how you will know if this change is happening and that it is working. Discuss the outcomes that have been agreed upon and decide when progress on these outcomes will be reviewed.

If you cannot resolve the issue with your child's teacher, the next step is to request a meeting with the school principal. Let the principal know your concerns. Also let the principal know that you have discussed this issue with the teacher and have not been

able to come to a satisfactory agreement. The teacher should participate in the meeting with the principal. This will ensure all partners can contribute information, perspectives and possible solutions.

What happens if I can't resolve the problem at the school level?

If the issue cannot be resolved at the school level, the Alberta School Act, states that school boards must have a process for appealing school district decisions that significantly affect a child's education, such as disagreements over identification of a special need or program placement. The school principal can provide information on the appeal procedure in your district. Typically, parents and school staff prefer to work out agreements collaboratively at the school level, but in some instances the next step is an appeal at the district level.

If an appeal to the school board is completed and parents disagree with the decision

and feel it does not meet the learning needs of their child, they may write to the Minister of Education and ask for a review of the board decision. School boards have an obligation to advise parents of their right to request that the Minister review the board's decision if they are not satisfied with that decision.

If the Minister does review the case, the review will only assess the situation for one school year, because that situation may change over time. There are very few reviews by the Minister each year. In most cases, parents and educators prefer to resolve differences at the school and district level.

Key Points

1. Parents have a right and a responsibility to be involved with their child's education.
2. Parents have a right to request a meeting at the school if they feel that there is a problem that they would like to have addressed.
3. There is a step by step process to resolving conflicts that includes the following:
 - a. Meeting with the teacher to try to resolve the problem
 - b. Meeting with the school principal if the problem isn't resolved with the teacher
 - c. Appealing the principal's decision at the school district level
 - d. Appealing the school district's decision at the provincial level.
4. Parents find the following steps helpful when trying to resolve conflicts:
 - a. Coming prepared to the meeting with questions and concerns
 - b. Taking time to consider what you want the outcome of the meeting to be
 - c. Focusing your concerns on your child's learning needs
 - d. Being prepared to work together to generate solutions
 - e. Including your child if at all possible to come up with solutions
 - f. Asking questions and taking notes
 - g. Requesting a follow up meeting
 - h. Giving the school time to implement the solutions
5. Some parents find it helpful to bring a family member, Elder or trusted family member to the school to help them advocate for their child.

Food for Thought

Reflect on the following questions to consider how you might approach any concerns or conflicts that you may be experiencing.

- 1. Are there any situations that are creating conflict for me or my child?**
- 2. How do I handle conflict? Am I able deal effectively with conflict? If not, what could I do to help resolve conflict with my child's teacher or school?**
- 3. Who can I turn to for help? Is there a family member or friend that can help me to resolve conflicts in a positive way?**
- 4. What have been the outcomes of conflict in the past? How can I improve outcomes in the future?**

References and Resources:

The Learning Team – A Handbook for Parents of Children with Special Needs, 2003 <http://education.alberta.ca/admin/special/resources/learningteam.aspx>

The Journey – A Handbook for Parents of Children Who Are Gifted and Talented, 2004 <http://education.alberta.ca/admin/special/resources/journey.aspx>

Our Words, Our Ways: Teaching First Nations, Métis and Inuit Learners <http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

Unit 6

Bullying

“I came around the corner of the school while on supervision and noticed a large group of students standing beside Sophie, a student with FASD. They were facing a smaller group of students who were calling Sophie names. I heard some of the students tell the smaller group of students to leave Sophie alone and that bullying her wasn’t okay. The students who were bullying stopped and walked away. A few of the large group of students asked Sophie to come and play with them. Sophie smiled, stopped crying and went to play with them. I was so proud! Our students were really learning how to deal positively with bullying!”

*(*true story from a rural school in Alberta)*

Parents Rights and Responsibilities

Everyone has a role to play in stopping bullying and making our school communities safe and welcoming for all students. Bullying behaviour is hurtful and harmful and is NOT just something that children have to endure as part of growing up. Children and youth with Fetal Alcohol Spectrum Disorder (FASD) may be especially vulnerable to being bullied and/or developing bullying behaviour. They may be vulnerable because they lack social skills, are easily influenced by peers or have not devel-

oped the ability to empathize with others.

It is important for parents, caregivers, educators and the other adults in children’s lives to recognize that they may not see the bullying behaviour; it is not always easy to spot bullying in action. Recent research shows that much of bullying behaviour happens without an adult actually witnessing it. However, when peers intervene, they are successful in stopping bullying about half the time. Without guidance, however, they are just as

likely to intervene aggressively as prosocially. A focus of intervention, therefore, is to teach the children appropriate ways to handle the situation. (Peplar and Craig - http://psycserver.psyc.queensu.ca/craigw/Craig_Pepler_2000_

REPORT_Making_a_Difference_in_Bullying.pdf) That is why parents and teachers have to rely on good communication with our children and students to coach them on how to prevent and stop bullying.

How can I tell if my child is being bullied?

Children don't always tell parents they're being bullied because they're embarrassed or afraid the person who is bullying will get back at them. Children may believe they must remain silent in order to belong.

Your child's behaviour may be a clue to bullying even before they are willing to talk about it. Warning signs include:

- being afraid to go to school or complaining about feeling ill in the mornings
- skipping school
- coming home with clothes or books destroyed or missing
- coming home with unexplained bruises or cuts
- becoming withdrawn or beginning to bully other children

What can I do if my child is being bullied?

If you suspect your child is being bullied, ask her directly. Are there any bullies in your class? What kinds of things do they do or say? Who do the bullies pick on? Do they ever bully you? If the answer is yes - here are seven ways to take action right away.

1. Offer comfort

Let your child know you are there to support them, and that you will do all you can to help him feel safe. Let your child know the bullying is not his fault. Encourage your child to always ask for help and not to stop until he gets it, whether it's at school, at work or in the community.

2. Work with the school

Contact the school immediately to make sure the situation will be monitored so your child will be safe. Check the school's plan for supervision and intervention during recess and noon hour. Work with the school to implement an anti-bullying program involving students, teachers, administrators, parents and community members.

3. Make arrangements for safety

Identify a safe adult and a safe place at school, so your child knows where to get help. If the bullying happens on the way to school, arrange for your child to go with older, supportive children, or take them to school yourself until the threat of bullying is gone. Help your child develop strategies for avoiding vulnerable situations. Encourage him to stay with friends on the playground and in the hallway, and avoid isolated areas such as empty classrooms or areas of the playground that are far away from supervisors.

4. Help develop confidence

If your child is shy or doesn't have friends, encourage her to participate in clubs or social groups that share similar interests. Encourage your child to invite other children to your home, one at a time. Suggest your child contact another student the night before to ask if they would like to play at recess or noon. Children who bully tend to pick on children who are isolated, so everything you can do to help your child develop confidence in her social skills will help. Tell your child to always be with a group and not be alone anywhere that bullying could happen.

5. Practice effective responses

Work with your child to practise what to say and do when someone is bullying her. For example, she could say, "Stop it. I don't like it" firmly and walk away and get help. Encourage children to stay calm and not to fight back. The person who is bullying wants attention and fighting back gives him or her they want. Fighting back can also make the situation worse.

6. Build self-esteem

Create opportunities for your child to do something well - a task, a sport or hobby - and praise him for it to help build self-esteem. Research shows that kids who survive bullying had at least one adult that cared about them, and the child realized that they were competent in something. Another way to build confidence is to find opportunities for your child to mentor younger children.

7. Communicate

Encourage your child to talk with you about her feelings and ideas. This may take numerous attempts before your child is able to break free from the fear of tattling.

What shouldn't I do?

If your child is being bullied there are five things you shouldn't do:

1. Don't minimize, rationalize, or explain away the bully's behaviour.

If you do, you are inadvertently telling your child he is in this all alone.

2. Don't rush in to solve the problem for your child.

Unless your child is in physical danger, taking over the situation will convey to your child that she really is helpless, and convey to the bully that your child really is a vulnerable target. Ensure the safety of your child, but also give her the tools to fend off and stand up to the bully in appropriate ways.

3. Don't tell your child to avoid the bully.

Avoidance can be a short-term but not a long-term solution. Your child can't keep running and hiding remaining in fear of the bully. They will become an ever-weakening victim.

4. Don't tell your child to fight back.

Don't teach your child that fighting is the answer. Defend, yes. Be assertive, yes. But tell him to use his head and feet first. "This is a dumb place to be, I'm out of here." Kids who act assertively are more successful in counteracting the bully than those who fight back.

5. Don't confront the bully or bully's parents alone.

The bully learned to bully somewhere, maybe from her parents. They may be defensive, uncooperative and blame the victim. Enlist the help of the school.

If these steps don't work

If you have tried the above options and your child is still overwhelmed with a negative atmosphere at school, consider giving your child a new start at a new school. If that is not an option, reassure your child that you will keep working until the situation is resolved.

How can I tell if my child is bullying others?

Here are some possible indicators that your child may be engaging in bullying behaviour:

- lack of empathy—not understanding or caring if someone is hurt
- extra money or clothes, or boasting about taunting someone
- passing off teasing someone as a joke
- children or youth grouping together and intentionally leaving others out
- aggressive behaviour with peers, such as yelling, hitting or throwing
- laughing when others get hurt
- name calling of siblings or friends
- aggressive, angry behaviour towards family, school staff or other adults

What causes bullying behaviour?

The following may contribute to bullying behaviour:

- past experience of being bullied
- lack of attention, rejection or marginalized feelings
- mental, emotional or physical abuse
- exposure to excessive violence through media or games
- lack of supervision when interacting with peers
- difficult temperament, attention problems, hyperactivity
- family stress or witnessing family violence
- lack of positive role models

What can I do if my child is bullying others?

Bullying is destructive—not just for the students being bullied, but also for those who witness bullying and/or demonstrate bullying behaviour. Recognizing bullying in children and youth is an important step in stopping and preventing the emotional, physical and social

scars that can last a lifetime. Bullying is not a discipline problem, it's a relationship problem. Bullying is a learned behaviour, and children need help in fostering more positive relationships.

A child who bullies must learn it is unacceptable and there will be consequences. If you learn your child is bullying, here are 11 ways to take action:

1. Stay calm

Try to get as much information as you can from teachers and others about your child's behaviour. Avoid blame and focus on potential solutions.

2. Be firm

Let your child know firmly that bullying is not acceptable, and that it must stop. Discuss positive and negative power, and how her actions can be helpful or hurtful. Stress that you still love her and will help them to change the bullying behaviour.

3. Ask why

Talk to your child about how bullying affects the victims. Ask your child how he would feel if his was being bullied. Ask why he bullies others and what might help to change that behaviour.

4. Encourage expression

Encourage your child to express her feelings. Find out if there is something troubling your child and try to help solve the problem.

5. Use non-violent consequences

Work out an effective, non-violent consequence that is appropriate to your child's actions and age. For example, take away a privilege.

6. Aid reconciliation

Work out a way with your child to help make up to the victim for the bullying.

7. Set rules

Keep an eye on your child's activities, whereabouts and friends. Set clear but reasonable rules, and give immediate feedback on progress.

8. Seek Help

Cooperate with the school in working to change your child's aggressive behaviour. Keep in touch with teachers/counsellor to find out how he is doing.

9. Spend time

Spend time with your child and offer praise when she shows non-violent, responsible behaviour. Work with her to find non-violent ways to deal with anger and "let off steam."

10. Monitor TV

Make sure your child does not see violence between family members and monitor television and video-game playing for violent content. Encourage discussion about suitable role models and heroes.

11. Reflect

Examine your own behaviour to see if you are using your power as a parent appropriately. Remember that you are a powerful role model in your child's life. Practice healthy interpersonal skills in your relationships in the family and in the community.

What if my child is a witness to bullying?

Children who see another child being bullied may be reluctant to interfere or tell adults for fear that the bully will try to get even with them. But silence encourages bullying. If your child witnesses bullying, here are five ways to take action:

1. Set a caring example

Talk with your child about how the victim must feel. Try to help her feel empathy for others. Set a good example by letting your child see you care for others.

2. Encourage support

Talk with your child about the importance of standing up for others. Point out that if enough children stand up to the child bullying, he will have to change.

3. Explain the need to tell

Encourage your child to report bullying to an adult. Explain that there is a difference between tattling and reporting to prevent another child from being hurt.

4. Encourage solutions

Get your child to talk about what might stop someone from bullying. For example, she might create a distraction by changing the subject or suggesting a game.

5. Help assess the situation

Encourage your child to speak up for a bullying victim. But also help her determine when a situation is dangerous enough to go for help immediately.

What can I do about cyberbullying?

Because bullies tend to harass their victims away from the watchful eyes of adults, the Internet is the perfect tool for reaching others anonymously—anytime, anyplace. This means for many children and teens, home is no longer a refuge from the cruel peer pressures of school. To help prevent cyberbullying, you can:

- Learn everything you can about the Internet and what your child is doing online. (Visit getwebwise.ca and weron2u.ca for more information.) Talk to her about the places she goes online and the activities that she is involved in. Be aware of what your child is posting on websites, including her own personal home pages.
- Encourage your child to come to you if anyone says or does something online that makes him feel uncomfortable or threatened. Stay calm and keep the lines of communication and trust open.
- Talk to your child about responsible Internet use.
- Teach your child to never post or say anything on the Internet that he wouldn't want the whole world, including you, to see.
- Create an online agreement or contract for computer use, with your child's input. Make sure your agreement contains clear rules about ethical online behaviour.
- Install blocking software, but be aware that children may find ways around them.

If your child is being cyberbullied, here are some ways to take action:

- Watch for signs that your child is being cyberbullied. A reluctance to use the computer, cell phone or go to school may be an indication.
- If the bully is a student at your child's school, meet with school officials and ask for help in resolving the situation.
- Report any incident of cyberbullying to your Internet Service Provider (ISP).

- If your child is bullied through a cell phone, report the problem to your service provider. If it is a persistent problem, you can change the phone number.
- Encourage your school's bullying policy to include harassment from mobile and Internet technology. Find out what your school is doing about bullying and offer ways to support the school.
- Report any physical threats to your child to the local police or RCMP detachment. Talk with teachers, other parents and community members to work together to address issues of bullying in your school and community in a positive and proactive way. By working together, caring adults can foster a school climate where every student can feel cared for and safe.

Key Points

1. Bullying is NOT a normal part of growing up and no child or person should have to deal with it.
2. Children and youth with FASD may be especially vulnerable to bullying because they lack social skills, are easily influenced by peers or have not developed the ability to empathize with others.
3. Bullying is a relationship problem, not a discipline problem. Bullying is a learned behaviour, and children need help in fostering more positive relationships.
4. Recent research shows that much of bullying behaviour happens without an adult actually witnessing it. That is why parents and teachers have to rely on good communication with our children and students to find out if bullying is occurring.
5. Warning signs that a child is being bullied include:
 - being afraid to go to school or complaining about feeling ill in the mornings
 - skipping school
 - coming home with clothes or books destroyed or missing
 - coming home with unexplained bruises or cuts
 - becoming withdrawn or beginning to bully other children
6. Strategies that parents and caregivers can use if their child is being bullied include:
 - offering comfort and reassurance that they will help their children
 - working with the school to prevent and stop the bullying
 - make arrangements for safety so their child does not get hurt
 - helping to develop confidence and build self esteem
 - practicing effective responses to the bullying
 - communicating frequently with their children and encouraging them to talk about their feelings.

7. There are warning signs that may indicate that children are engaging in bullying behaviour and include:
 - lack of empathy—not understanding or caring if someone is hurt
 - extra money, clothes or boasting about taunting someone
 - passing off teasing someone as a joke
 - children or youth grouping together and intentionally leaving others out
 - aggressive behaviour with peers, such as yelling, hitting or throwing
 - laughing when others get hurt
 - name calling of siblings or friends
 - aggressive, angry behaviour towards family, school staff or other adults.
8. There are many strategies that parents and caregivers can use to help prevent and stop bullying behaviour in your children and include:
 - letting your child know that bullying is not acceptable at any time or place
 - remaining calm and asking your child why they are bullying others
 - setting rules, helping with reconciliation and monitoring violence on TV programs, movies, games or in other activities
 - reflecting on your own behaviour and teaching empathy to your children.
9. Children who witness bullying are also vulnerable to its negative effects. They need to be taught how to speak up and stop bullying in a safe and responsible manner.
10. Because bullies tend to harass their victims away from the watchful eyes of adults, the Internet and “cyberbullying” is the perfect tool for reaching others anonymously—anytime, anyplace. For many children and teens, home is no longer a refuge from the cruel peer pressures of school. Parents can look for signs of cyberbullying and put strategies in place to prevent and stop it.

Food for Thought

Consider the following questions to reflect on whether your child might be a victim or perpetrator of bullying.

- 1. What do I know about bullying? What are my thoughts and attitudes about bullying?**
- 2. Has my child ever talked to me about bullying? What did I say at the time? Do I need to talk with my child some more and what will I say?**
- 3. Have I ever seen any signs of bullying in my child? Are there signs that my child is bullying others?**
- 4. My child loves to play on the computer and text on his phone. Do I know what she’s looking at and who they’re communicating with? How can I talk with her about cyberbullying?**
- 5. What is happening at my child’s school related to bullying? How can I participate and what information would be good to share?**

References and Resources:

Adapted from parent fact sheets on the Bully Free Alberta website at <http://www.bullyfreealberta.ca/>

Re: Defining Success: A Team Approach to Supporting Students with FASD (2009) <http://education.alberta.ca/admin/special/resources/re-defining.aspx>

6

Module 6: Transition Planning

Unit 1: Introduction to Transitions

- Topic 1:** Introduction
- Topic 2:** Importance of transition planning
- Topic 3:** How to make transitions easier
- Topic 4:** How to develop a transition plan
- Topic 5:** Antecedents: Identify antecedents that predict the behaviour

Unit 2: Home -and School- Based Transitions

- Topic 1:** Home to preschool or child care
- Topic 2:** School-based transitions
- Topic 3:** Guardianship and trusteeship
- Topic 4:** Independent living
- Topic 5:** Employment
- Topic 6:** Other options/ Alternatives to employment
- Topic 7:** Finances and funding



Unit 3: Developmental Transitions

Topic 1: Introduction

Topic 2: Puberty

Topic 3: Sexuality/ Sexual development

Topic 4: Relationships

Unit 5: Life Transitions

Topic 1: Introduction

Topic 2: Divorce

Topic 3: Loss

Topic 4: Moving

Topic 5: A new baby in the family

Unit 4: Medical Transitions

Topic 1: Introduction

Topic 2: The culture of families with medically complex children:
Metaphor

Topic 3: Roles and responsibilities

Topic 4: Natural supports

Topic 5: Important issues to think about in relation to medically complex children moving to adult services



Unit 1

Introduction to Transitions

Change is hard. Leaving a place of comfort and familiarity to walk into “the great unknown” is intimidating and frightening. It takes strength, courage and confidence; but mostly, it takes guts.

Introduction

Transitions can be challenging for children and adolescents living with disabilities and their families. The journey through childhood, to adolescence and into adulthood is complex. While most parents may have mixed feelings when their child starts day care or preschool, when that child has a disability, it can be even more stressful. As the child grows, the anxiety caused by transitions continues. Transitions can take many forms – moving from one grade to the next, moving from one school to the next, and moving to adult services and the world of work. There are other transitions in life that children and youth need to learn to cope with – family changes, such as the birth of a sibling, the death of a loved one, or the divorce or remarriage of parents. Each life stage also carries with it some changes.

Adolescents with disabilities and their families need to learn to navigate new environments, and to identify new resources and supports. Each family responds differently to periods of transition and the stressors associated with this experience. Parents may find it difficult to leave behind the services and health care/support workers who have been with them since diagnosis. Young people with disabilities also struggle with changes in support and care networks. Parents must support their child through this process while also negotiating the experience of change and transition. The different types of transitions and specific strategies will be explored here in more detail in this module.

Importance of Transition Planning

Our most successful transitions have always included a great deal of preparation, which includes careful planning to anticipate opportunities and challenges. Meeting the people involved is critical to this preparation. This provides everyone with an opportunity to think, plan and problem solve prior to the child arriving in the new setting.

Children and youth with disabilities require careful planning for a smooth transition. To develop an effective transition plan which leads to more successful outcomes, it is important to start early! Beginning the transition process early allows adequate time

to address challenges, strengthen skills and develop action plans. This is especially important for the transition following high school, as many existing services and supports for children will no longer be available after the adolescent's 18th birthday, possibly leaving the adolescent and family without services and struggling to catch up. The transition plan should also provide adequate time for children and parents to learn and practice the skills and routines that will facilitate a smooth transition.

Planning for Transition

According to the Alberta Children and Youth Initiative's 2006 Guidelines for Supporting Successful Transitions for Children and Youth (pg. A.1-1), some specific strategies for supporting successful transitions in children and youth with disabilities include:

- Ensure basic needs are met. (Basic needs include: a place to live, supportive relationships and good nutrition).
- Maintain and encourage positive relationships.
- Provide support and resources to young people in their new environment and modify or adapt routines, as needed.
- Provide choices and involve the young person in the transition process as much as possible to promote and support self-advocacy. (Self advocacy is the process of a young person having a voice and say about the transitions in their life, while recognizing that some choices need to be guided by families and professionals).
- Support the need for increased independence and help children and youth create their own identity. (Each child has their own personality, unique needs and desires for their life).
- Ensure that all transition plans are coordinated and integrated, and information is shared with parents and with everyone involved.
- Prepare for transitions and ensure consistency within and between environments.

Decision Making and Problem Solving – An Important Process

How do you engage your child in decision making? It is important to think about this when life transitions are taking place. Consider the ways that you have included your child in decision making and problem solving throughout their life. It is important for even the youngest child to begin to exert their own capacity for independent growth. This process occurs over a lifetime of a child through each developmental gain and experience that in a

moment, reflects the notion: “I did it.” This is the experience of growth and change. It may not be expressed in words, but when it happens, both parent and child know an achievement has occurred. Examples of decision making can be as simple as your child being involved in choosing the clothes she will wear to school, or what she would like in her lunch.

How to Make Transitions Easier

The level to which a young person is engaged in transition is dependent upon the nature of the disability. For youth with severe disabilities, this needs to be a guided process, relying on supports that have seen the young person through to adulthood.

- Let your child know that it is normal for times of transition to be difficult, but you will work through it together. Review what changes to expect and how you are going to work through them.
- Identify a list of specific changes and reflect on how to talk about each of these changes with your child.
- Gather information about what programs and supports your child may be eligible for.
- Encourage your child to express her feelings, emotions, thoughts, and worries regarding the changes she is experiencing.
- Encourage relationships with peers facing the same changes and challenges. If possible, consider the use of online peer support groups or discussion boards for youths with disabilities, if available.
- Help your child take an active role in problem solving by including him in the decision-making process. Encourage him to talk about concerns he has about the transition.
- Provide opportunities for problem solving in a safe environment. For example, consider the ways in which you involve your child in decision making and problem solving. What are your child’s strengths in making decisions? In what areas does she require support in making decisions about her life? The decision making process is an integral part of problem solving. Providing opportunities for decision making will promote confidence in your child.

- Recognize that it is often more difficult for parents to deal with transitions than their child. This reflects their concern and worry about the safety and security of their child. Talk about these concerns with family, friends and professionals who are in your life.
- Involve your child in activities that promote self-awareness, confidence, and self-advocacy. Encourage him to express his feelings and desires on an ongoing basis to ensure his participation in, and satisfaction with, the transition planning process.
- Be proactive. Develop a transition plan that works for your child, family, service providers and school, well before the transitional period.

How to Develop a Transition Plan

A transition plan considers the needs of the person at its centre – the young person with a disability. The purpose of a transition plan is to identify goals, paths to achieving goals, the persons involved in this process, as well as timelines.

A clear planning process helps everyone. Children and youth with disabilities need to be as involved as possible in the planning process as it is about their life. Effective and comprehensive transition plans are crucial to:

- (1) Build a sense of community;
- (2) Respond to the needs and concerns of the individual; and
- (3) Provide appropriate and effective approaches to guide the transition process.

Transition plans lead to more successful outcomes and experiences for children and youth with disabilities, who experience greater difficulty in achieving smooth transitions through life and school.

Person-centred planning is the best strategy for transition planning. The purpose of person centred planning is to ensure that the voice of the young person is central to decisions being made about their lives. This involves a process of constant review, learning and listening. Person-centred planning focuses on short-term goals and the long-term future, taking into account your child's needs, goals, thoughts, concerns and opinions. Consulting with family and friends and others within your child's personal network is also important.

Supporting your child to give input into the services and support he receives builds confidence and strengths, encouraging him to take a more proactive role in the direction of his life. Furthermore, engaging everyone in the process ensures that those who are making decisions understand, and take into consideration, your child's unique experiences and interests when planning.

The Alberta Children and Youth Initiative (ACYI) released a report entitled Transition Planning Protocol for Youth with Disabilities: Your Guide to Reaching New Heights in 2007 to promote transition planning. The report found that the current literature is consistent in recommending six best practice characteristics for transition planning in youth with disabilities:

1. Person-centred planning;
2. Youth involvement;
3. Family involvement;
4. Community involvement;
5. Identification and use of a transition coordinator; and
6. Inter-agency collaboration.

Knowing and understanding the issues you will face with each transition helps you become a strong and effective advocate for your child. Having this knowledge will enhance the experience of transitions.



Unit 2

Home-and School-Based Transitions

How many more people will I have to give my child's history to?? A new teacher and support staff every year, school nurse, school administration, medical specialists, clinic nurses, therapists.....don't these people ever talk to each other??

Home to Preschool or Child Care

Preschool or child care is designed to help children transition from life in the family to the school system. Preschool programs and child care early in life set the stage for the future and are very helpful in the development of your child's communication, problem-solving and thinking skills, and to familiarize them with the routines and rhythms of school life. It is common for most children with disabilities to be involved in early intervention as determined through medical assessment. While many parents opt for home-based programs, other children receive out-of-home child care, or attend a preschool program before elementary school begins. Many preschool programs

are aimed at enhancing developmental skills by providing early intervention therapies. They also provide your child with the opportunity to spend time with other children, and to develop language and social skills. Early learning educators are aware of the developmental needs of young children and are prepared to help children and parents cope with transitions. As this may be the first time that you are leaving your child to the care of another person outside of your home, it can be stressful for you and for your child.

Some ideas to consider:

- Spend some time in the program to become familiar with how it is organized.
- Ask what supports are available to parents whose children are in the program.
- Provide some ideas of activities and routines where your child may need to be supported, such as meals and toileting.
- Spend time when your child begins, but be careful not to stay too long. Negotiate this process with the staff to determine what works best. Be aware that the program staff is skilled with supporting transitions. Express your concerns to the educators and ask them for assistance in making the transition smoother. If your child is not coping with the change, speak with the educators and director to develop a plan around these concerns and required supports. There may be some adaptations required both at home and school to make this process easier for your child.
- Remember that your child will likely go through an adjustment period and then, over time, settle into the new routine. Some children adapt more quickly and easily than others. Often children experience excitement and anticipation about going to their program. Children are social and they often enjoy being with their peers and teachers. These early experiences establish expectations and routines for the many years of school life ahead.

Home to Preschool or Child Care

On paper, our child looks pretty challenging. Prolonged and severe seizures, often requiring transport to hospital, medication administration, tube feeds, specialized diet, non-verbal, non-mobile, no formalized communication system. The school was justifiably nervous! What the paper work does not show is that our child is very engaging and responsive to his peers, able to learn and loves to laugh. Once the staff at the school met him, they were much more willing to accommodate him in the school. They recognized the

influence and impact that he could have on his classmates and the school community.

For us, a face to face meeting and an open and honest discussion of our son's needs, which took place far in advance of his first day of school, was the most important factor in his success at our community school. We were willing to meet the school half way and enter into a partnership to provide the best possible educational experience for him which met our expectations and the schools capacity. Read about one parent's Tips for Successful School Transitions

The transition from home or preschool to school is a major event in the lives of both students and parents. The stress created by these transitions can be minimized by gathering as much information as possible about the process. It is important to recognize that transition is a part of daily life and going to school for 12 years or more is a critical

experience in the life of your child. Planning is important as this helps both the child and parents to ease into the process. The goal of planning for entry to school is to assist in creating a positive atmosphere to support your child's learning and to help your child adjust to the school setting.

Children make many transitions during their years of schooling:

- home or preschool to school
- elementary to junior high school
- junior high to high school
- high school to post-secondary education, the workforce, adult day programs, or alternate support arrangements

The Government of Alberta Homepage has a Back to School Information Kit (2010-2011) that is located online at <http://www.education.alberta.ca/resources/backtoschool/parents.aspx>



The section on Tips for Parents may be helpful in structuring the school experience for your child.

Communication is important! As your child starts out on the long road of schooling, it is important to be proactive in the planning of transitions. This means parents need to be involved and be in regular communication with your child and her teachers, support workers and school administration, as required. The purpose of this communication is to ensure that your child's needs are being met. Attend parent-teacher conferences, have planning meetings with school staff, and document meetings with the school to ensure you are keeping track of activities and goals for your child.

a) PRESCHOOL TO EARLY CHILDHOOD SERVICES (ECS) or KINDERGARTEN

Do what moms do best – worry in advance. Or taking a more positive spin on it – Be prepared.

Start thinking about the school your child will attend at least one year in advance. The year prior to kindergarten visit the school and see what the physical layout looks like and meet the principal. In my experience every principal we have dealt with wanted our child to have a positive learning experience. If this is your first year entering the school system the principal should be able to put you in touch

with the proper CBE contacts. You may be working with a team: OT, PT, Speech Therapist

A child's first day at kindergarten is an exciting and emotional event for the whole family. Kindergarten is the first step in grade school and is designed to further increase your child's skill and independence. With a little preparation and planning, you can help ensure that your child's transition from preschool to kindergarten is a positive and rewarding experience for everyone.

Challenges:

- The school's location and design will be different and your child will not be familiar with the new environment. The classroom layout will also be different from the preschool and it will take your child time to adapt to the new environment.
- The other students in your child's class may not have had experience with her particular disability and may be unsure how to interact with her.
- The social nature of kindergarten means that young children must learn to participate in group activities and share with others. This change can be particularly difficult for children without siblings or who do not have previous exposure to play environments with other children.
- Adapting to a new routine with more time spent at the school can be difficult for both the child and parents.

Strategies:

- Allow your child to become familiar with the school by driving past it as often as you can during the summer. Visit the playground frequently over the summer.

- Tour the school during the summer if possible, even if your child visited on registration day, just to get him/her more comfortable in the building. Many schools are staffed at different times over the summer by the principal, assistant principals, and other administrators. Ask if you can bring your child for a visit prior to school starting. Schools often open at the end of August and may be able to accommodate this request at that time.
- Bring up school in conversations at home as much as possible. Talk about the fun things your child will get to do. Don't express regret that he/she is starting school. Make sure he views it as a positive step.
- Talk to the kindergarten teacher about having a discussion with the class about your child's disability and the best way to interact with your child.
- Make shopping for school supplies a fun experience. Get a list from the school of what is allowed and expected. Let your child make some choices about the color of her backpack, the type of pencil case, etc.
- Start the school bedtime routine a month before school starts. You can introduce the new bedtime gradually, having your child go to bed just five or 10 minutes earlier each night.
- Check out books from the library that help ease jitters about starting school. Recommended books include: *The Night Before Kindergarten*, by Natasha Wing, and *The Kissing Hand*, by Audrey Penn.
- Attend every open house and meet-the-teacher event offered. Ask for information on joining the Parent Council. It is a great way to meet other parents with children in the same class and to learn about what's going on at school.
- You can do arts-and-crafts projects with your child during the summer to get them more comfortable using scissors, markers, and other supplies that they will use in kindergarten.
- Work with your child throughout the summer on academic skills, such as writing his name or reading letters.

Getting ready for kindergarten doesn't have to be the main focus of your summer; however, taking time to familiarize your child with the school and what to expect will go a long way toward supporting a smooth transition.

b) KINDERGARTEN TO ELEMENTARY SCHOOL

Kindergarten is designed to ease children into the structured learning environment and routines of the formal school system. However, some children only attend kindergarten on a part-time basis, so the transition to

full-time school can still be a bit of a shock. No matter how well your child adapted to life in kindergarten, it is worth taking some time to prepare her for life in elementary school.

Challenges:

- Locations will be different: a new classroom, office, bathrooms, lunchroom and play spaces.
- Your child will need to meet and adjust to new teachers and classmates.
- Most kindergartens are traditionally half-day programs. The transition to a full day away from home at the school can be overwhelming and tiring for some children. Energy and fatigue are important issues to watch for in some children. Monitor how your child is adapting and create supports as required in collaboration with the school staff.
- The elementary curriculum is more structured and academic-focused.
- In the early grades, children are still adjusting to a social world outside the home. They form new friendships, learn about teamwork and may find themselves developing special interests and skills.

Strategies:

- Talk to your child before school starts and tell her where she will be going and what she will be doing. Talk openly about school.
- Take your child to visit the school on a few occasions. Find out where the important places are and show your child how to find his classroom, the toilets, the lunchroom, office and play spaces.
- Attend orientation, buddy and transition programs at the school if they are available. These services can be a great way to build confidence.
- Find out the names of other children who will also be starting and invite them to play with your child beforehand. If possible, talk to neighbors whose children will be going to the same school.

- Teach your child about the rules he will need to follow, so they don't come as a surprise on the first day. Practice following these rules at home throughout the summer.
- Build your child's co-operation and team skills by playing games that involve taking turns. As much as possible, offer your child natural opportunities to build skills that enhance her readiness for school and, at the same time, keep it fun.
- Teach your child to ask for help when he needs it in the new environment. Review how to ask for help if there is a problem. Identify to the teachers the way your child communicates when distressed or upset, so they are prepared and know what to anticipate.
- Within the new environment some problems may emerge that are not anticipated. Set up a means of communication, such as a communication book that records how your child's day went. This allows you to know about your child's day and to process the day with your child, as well as prepare for the next day.
- In some rural and urban communities, schools exist that go from kindergarten to grade 9 (K-9). One of the benefits of this type of school is that it minimizes the concern of changing schools, and is often a stable environment for the child for many years. If this is an option for you and your family, consider this possibility.

NOTE FOR PARENTS: You will need to think about how you will spend your day and adapt to your child's school transition, particularly if you are a stay-at-home parent.

The time you invest in transition planning over the summer before school will help ease the transition into the first grade for both you and your child.

c) ELEMENTARY TO JUNIOR HIGH SCHOOL

Changing from Elementary to Junior High was the biggest change as you generally go from one teacher/one classroom to many teachers/many classrooms.

When our daughter, Jenica, was in grade six we started preparing for her to start Junior High School. Jenica's biggest concern was that she didn't want to "stand out in the crowd". She warned us several times not to "make a big deal" out of anything. But to us, this transition was one of the scariest. She was going from one teacher/one classroom to many teachers/many classrooms. We were worried about bathroom access and accessi-

bility, classroom door width, classroom location, and elevator availability. We took Jenica to meet the school principal and resource teacher in June to discuss issues and needs. We planned this for the school's organization day so that students weren't there. That way Jenica was comfortable testing accessibility without feeling like she was the centre of attention. We had the opportunity to ask all our questions and to see how things would operate. Our planning in June meant that the first day of school in September, Jenica had all her supports in place. She was able to get around without needing a lot of extra attention.

The transition between elementary and junior high school is a time of many changes and adjustments. Junior high can be a confusing time for children as well as their parents. Your child is becoming more independent, yet needs your support as much as ever. While some parents may decide to allow their child more independence in some areas, it is essential that you stay actively involved with your child's school so you know what is going on for your child.

Changes to anticipate:

- Educational expectations become greater.
- Peer pressure escalates and it is important to know how your child is getting along with others. Concerns of bullying behaviour can emerge. It is important that parents be aware of this issue, as children with disabilities can be particularly vulnerable to bullying. Discuss this issue with the teacher or principal and make it explicitly clear that you need to be informed of any incidence of bullying behaviour that involves your child as a victim.
- Sexual curiosity and experimentation may become an issue.
- Parent involvement in your child's education at the junior high level is important in relation to academics, social experiences and to provide informed support.
- Going to junior high school is a major transition. You can support your child by monitoring school progress and responding to struggles that will emerge for young people in this stage of life.

Students making the transition into junior high school need to receive assistance prior to, during, and after the move so that their social, psychological, and academic well-being are protected and enhanced.

NOTE FOR PARENTS: Parents are encouraged to begin looking into programs for adults (18+) with disabilities by age 15 or just after the 16th birthday at the latest. Some programs may require your child to have certain skills before entering, such as self care and no (or manageable) aggressive behaviours. Other programs for youth with more severe disabilities will need to know what types of physical care and social supports your young person will require. There may also be long waiting lists for some programs. For more information about this transition to the adult world please refer to the "High School to Adult" section.

Challenges:

- It may be difficult to determine accessibility for youth with physical disabilities.
- Your child may have trouble changing classrooms and getting to class on time.
- There may be issues with navigating through the crowded halls in between classes – this issue relates to accessibility and needs to be determined at the outset of the year as it can become a safety issue for your child. Work out a process with the school that will meet your child's needs in relation to getting around the school.
- Your child may find it difficult to find her locker (they all look the same!) and open a combination lock. You may need to ask for an accommodation such as a key lock if a combination lock will not work for your child.
- Keeping up with school work can be very hard. Negotiate homework with the school if there are concerns that make this additional work challenging.
- Your child might need help finding the lunchroom, bathrooms, classrooms, office, and recreation spaces.
- Your child might need help getting on the right bus to go home after school.
- Your child may have difficulty reading the schedule and remembering which class to go to next.
- Personal safety can be an issue.

Strategies:

- Junior high schools hold orientation sessions for incoming students. Go the orientations or events at your school. If you miss orientation, contact the school to request the information that you may have missed.
- If a combination lock will not work for your child, talk with the school about how to work around this issue. If your child can handle a combination lock, buy one so he can practice over the summer. Once at school, he will have a new combination to learn, but with some practice, he can be confident he can get into his locker when needed.
- Talk to the school principal to see if it would be possible to visit the school a few times over the summer to orient your child. Make sure your child knows where her appropriate classrooms, bathrooms, and lunchrooms are located.
- Junior high schools have more opportunities for extracurricular activities. Talk to your child about what interests he would like to develop. What does he want to do in relation to participation in these activities? Take him to a couple of events to see what they are like when school starts. This is a great way for your child to connect with other students with similar interests and get to know the staff better.

- Familiarize yourself with how the junior high operates.
 - Do students have a different teacher for every academic subject?
 - Do students need to change classrooms regularly?
 - How does the school communicate with parents?
 - Are homework and project assignments posted online?
 - Gathering this information will help you guide your child through the first few weeks and track their progress.
- Help your child learn organizational skills. Many students who struggle in junior high have problems with organization. Give your child some summer responsibilities that will help her build time-management and other organizational skills. Ensure that your child knows to ask for help when needed. Make problem solving a collaborative process with your child. Then she knows you are there to support her. Identify key people in the school, possibly a peer mentor or teacher whom she can ask for help. It helps both parent and the young person to know there is help in the school environment when the parent is not present to respond to problems or concerns.
- If you want to be involved with the school, consider joining the Parent Council if this works in your busy life. Many parents think they aren't needed or wanted at the school, but teachers want parents involved. And, believe it or not, many children want their parents involved.

d) JUNIOR HIGH TO HIGH SCHOOL

This is a hard thing – recognize when, in some cases, your child needs more independence and less aide time. We are all very protective of our children but sometimes they don't want an aide by their side every minute of the day. Also, you don't want your child to develop a learned helplessness. Our child went from a full time aide, to sharing an aide in Junior High to not having an aide in High School. At first we weren't happy with the reduced aide time but we listened to our son and he was OK with it.

The transition from junior high school to high school is one that is just as important as the transition to adult life following high school. It is a critical time when adolescents move from smaller middle (junior high) schools to larger high schools, where the academic and social demands are higher.

Youth with disabilities can also experience many positive benefits in their high school program. Some of the benefits include meeting youth who want to work as peer mentors or "buddies." Some schools embed this type of experience into their high school curriculum, supporting the development of relationships and peer connections in the school setting.

Students and parents also become aware of growing pressures of the adult world as they enter high school. It may become increasingly more difficult for youth with disabilities to compete academically with their peers due to their disability. The classes become more difficult, the subjects change, and the workload becomes greater, all while the student is trying to cope with all the other difficulties that come with being a teenager. This is a time to focus on long-term planning

for your child. Consider carefully the courses that will be of benefit and interest to him. Work skills are often infused into high school curriculum. If participation in this type of program fits with the needs and desires of your child, encourage these types of experiences. For some young people, the academic program may need to be adapted for their particular needs. At the same time, the students (and their parents) are coping with all the physical, social and emotional struggles associated with being a teenager. Some students may also

begin to feel that they will not be able to meet graduation requirements, and may feel the school's curriculum and programs do not meet their needs. They may not feel encouraged by their teachers or family to stay in school. Thus, the transition into high school requires support from and collaboration among teachers, parents, counselors, personal supports for the young person and family, and even school system administrators.

Challenges:

- The transition to high school usually means a move to a different and usually larger building, with many more students, new teachers and support staff, and new expectations.
- Establishing new social connections, peer supports, and balancing school work and social life can be difficult.
- There may be growing pressure or curiosity to experiment with alcohol, drugs, and sexual activities.
- For parents, a challenge is the concern about the vulnerability of their child to peer pressure.
- High school students become increasingly more independent throughout high school, with less in-class support and guidance from teachers, to prepare for post-secondary education and employment.

Strategies:

- Ease the transition through social and emotional support from adults and peers. Youth with a greater sense of connectedness to the school, developed through positive relationships with peers and teachers, are less likely to engage in high-risk behaviours.
- Arrange a meeting before the start of school with the guidance counselor to discuss your concerns and ways to provide support to your child.
- Speak with school staff before classes begin to review your child's unique learning needs and strengths, and her individual program plan if she has one. Work together to create an environment in which your child can maximize her learning and minimize stress.

- If your child has a sibling in the same school, it is important to establish the role of the sibling for providing support. As the sibling is also going through the struggles of adolescence, it is critical to be clear about what types of supports she is willing and able to provide in the school setting. Work this out within the family by having conversations about concerns in the school setting, how to approach problems and advocate for the young person with a disability. Often these “natural supports” can work out very well if negotiated and all voices are heard in the discussion.
- Learn about the high school’s extracurricular activities and help your child practice or prepare for clubs or teams over the summer so he feels confident and excited to begin school. Encourage ongoing participation throughout high school. These activities are a great way to build confidence and make new friends in the school.
- Have an open conversation with your child about the risks and consequences of drug and alcohol use. There are resources for educating young adults with disabilities about these issues. Talk to your local service provider for adults with disabilities to obtain the appropriate resources for your child.
- Address issues related to sexuality as these are bound to emerge in high school. Encourage your child to envision their post-high school life and what they see themselves doing in adulthood. You may want to begin to think about life and opportunities after high school starting early, in grade 10 or 11, so that she can take the right courses and begin to check out opportunities as they progress through high school.

Resources in Plain Language for Supporting Young Persons with Disabilities

One community organization in Calgary, Vecova (formerly VRRRI), has developed a range of plain language brochures that address topics such as Bullying and Workplace Harassment, and Sexuality and Health Issues, amongst other topics. These resources can be found at the Vecova Website. Families may also want to access other resources about adults with disabilities, such as the Bridges magazine.

e) HIGH SCHOOL TO ADULTHOOD

As a family, we have spent the last 17 years figuring out how systems work and how to access supports for our son. We are finally feeling comfortable with our assembled team of doctors, specialists, speech language pathologists, occupational therapists, physical therapists, nurses, home care specialists, teachers, educational assistants, social workers, managers, respite workers, personal care attendants and child development specialists.

The day that my child turns 18, all the supports that we have worked so hard to find and access will be gone. We have to start over from the very beginning.

I am exhausted even thinking about it.

Leaving school and the transition to adult life in the community is difficult for every adolescent, and can be challenging and complex for those with a disability. This transition must consider what the adolescent hopes to do in the future and how they envision their life after high school. This transition must be a highly structured and planned process. Teachers can make recommendations based on their experience of working with and supporting your child, regarding referrals to adult programs.

Discuss with your young adult his short-term and long-term goals for the future, and where he sees himself after high school. (Note: All adolescents, even those without a disability, find this to be a difficult question). This can be a difficult question for an adolescent with a disability for several reasons: difficulty adapting to changes in routine and environment; difficulty understanding and making choices regarding goals and expectations in their future adult life; and limited choices and opportunities.

The transition plan for entry into adulthood should generally include the following elements:

- Specific goals for your child’s transition to post-secondary activities. The goals must be realistic and reflect your child’s strengths, needs and interests;
- The actions required currently, and in the future, to achieve the stated goals. The actions identified must build on your child’s strengths, needs, and interests;
- The person or agency involved in providing assistance in the completion of each of the identified actions; and
- Timelines for the implementation of each of the identified actions.

Challenges:

- There are many changing rights and responsibilities associated with coming of age, including:
 - Guardianship
 - Trusteeship
- New living arrangements may need to be arranged.
- Finding meaningful employment, program or post-secondary education placements may be difficult.
- There may be issues around financial support and funding.

Strategies:

- The most important thing to remember when planning transitions is to get started EARLY (by 16th birthday).
- Contact community support agencies in your area that work with disabled youth. Ask the agency best suited to meet your young person's needs and who to contact to begin transition planning. Ask for information about programs in your area for social/recreational, vocational/employment opportunities as well as life skills training.
- Talk with other parents who have gone through or are currently going through similar transitions. You may contact administrative staff at the high school to see if they can put you in touch with a parent who has already gone through the transition process. It is always helpful to talk to someone who understands the challenges firsthand so you can learn from them.
- Work with your child's service providers to develop a transition plan based on your child's current needs and skills
 - It is most important to focus on your child's strengths, passions and skills in their plan to ensure the resulting placement is meaningful.
- Begin investigating and applying for adult support services and funding early, to determine eligibility requirements and maximize funding possibilities.
 - Discuss and plan different funding and financial options available for your child based on current community/government support programs and your child's unique needs with your service provider or school.
- Most importantly, schedule in some relaxation and recreation time for your child with friends and family to balance the stress that accompanies transitions.

Tips for Successful School Transitions: Parents' Perspectives

Some things to think about:

- Is the school accessible? Check out the entrance, the washrooms, the lunch room, and the gym
- If you are driving your child is there a designated disabled parking spot?
- If your child will be bussed, find out how that is arranged
- Some children are sensitive to sound, listen to the bells
- If your child has allergies find out if the school has food restriction policies

- If the school knows who your child's teacher will be, you and your child should meet with her just prior to school starting. A one on one meeting can alleviate everyone's anxiety. The child should know where her coat hook is and it should probably be on the end
- If you child has an aide, meet with her prior to school starting. Discuss your expectations
- Consider ALL the schools your child will be attending and 1 or 2 years prior to changing schools visit the next school and check out the above. When our son was in grade 4 I realized the Junior High he would attend was two stories and did not have an elevator so I started talking to our Occupational Therapist and the Junior High principal. The school had an elevator by the time we got there.

Tips for starting a new school:

- Be reasonable
- Be open to suggestions – sometimes the school really does know best
- Be honest about your child's challenges and their strengths
- Be flexible – stuff happens and sometimes you just need to deal with it
- Don't discuss your worries /concerns in front of your child – we have a hard time dealing with the stress, imagine what it must be like for our children
- Develop social stories, scripts, and/or other visual prompts to support the child's move to a new school. Anticipate situations that could occur (feeling lost, crowded hallways, using a locker, changing for PE class, moving from class to class, having many teachers)
- If your child has medical needs, check medication administration and medication storage policies at the new school. Is there a private location in the school where the medication can be administered or the procedure completed? Create an opportunity to make classmates and staff aware of the medical needs of the student in a way that is respectful and protective of the dignity and privacy of your child.
- If your child struggles with communication or is shy, help him develop a scrapbook to share with his teachers and classmates. This is a fun way to let them know his interests and activities. An option is a talking (digital) photo album.
- If possible and if it is in the best interests of your child share the aide – if our son did not need the aide's assistance we wanted her to help the other children in the class. Everyone wins – the teacher, the other children and parents loved having their child in our son's class because they knew there would be 2 adults in the class.

- In the Elementary years volunteer in the classroom; be the room parent if possible. The better you get to know the teacher the better the communication will be.
- Participate on Parent Council – it really helps if school administration gets to know you. It is much easier to talk to the principal if they know you from Council and know you are a reasonable person
- The school gives a lot to our children so it's nice to give back – be a volunteer!
- In the higher grades the school wants the child to advocate for themselves but this doesn't always work. It's hard to tell teachers things aren't working. You and your child need to work together.

Transition Meeting to manage transfer from elementary school to junior high.

Our transition meeting covered the following:

PERSONAL

- Assistance with personal needs – how does he contact the aide if she is not in the classroom with him?
- Lunch - assistance
- Locker – is there a combination lock or key lock – is the child able to use either? Who helps getting coat on and off / storage of materials shelves, materials in classroom?
- Elevator – need a key before the first day of classes, does he ride the elevator alone, is there a phone in the elevator?

SCHOOL WORK

- Notes – can someone take notes for the child or will the teacher provide a set of notes
- Computer – can he bring his own, will he be able to connect to the Internet?
- Communication with teacher – via email or phone
- Organization -- agenda
- Class materials -- set up, pack up, transport of materials as he transitions from class to class. Can an extra set of textbooks be left in the classroom so he does not have to carry them every day?
- Time for tests – does he get extra time, where does he write exams?
- Curriculum – phys ed, options, is there a requirement to change clothes for phys ed?
- Expectations of curriculum-- handing in of material / quality of work / clear expectations

MOBILITY

- Getting back and forth from school
- Walking in school - Safety -- possibility of leaving class early/late to avoid the chaos of hall

Transition Plan Template

This template represents one way to approach transition planning. This is a place where a family and young person can begin to write down goals and plans. This form can be adapted and personalized to suit your needs. For example, add more lines for goals or any other information requiring more space.

Transition Plan for : (Insert Name of Young Person)

Goals What do I want to do after finishing high school?	Action Plan Who needs to be called for each goal?	Action plan steps What steps are required to mobilize the plan?	Person responsible Who is going to make the call or contact?	Timeline When does this activity need to be done? Identify a date for completion. Also, record dates of contact made with agencies or professionals.
My Goals	Persons to Contact- Phone Number and/or E-Mail	Action Plan Steps	Person Responsible	Timelines (date referral needs to be made), Dates Contact Made, and Follow Up
1		1. 2. 3. 4.		Date referral made: Date contact made: Follow up required by (date):
Goals	Action Plan	Action plan steps	Person responsible	Timeline
2				
3				
4				

Contact Information Generally Required When Making a Referral – Record Everything Here to Save Time Looking Up Numbers.

Personal Information	
Your Name:	
Home Address (including postal code):	
Home Phone Number:	
Cell Phone Number:	
Home E-mail:	
Health Care Number:	
Blue Cross Number (or health insurance benefits plan number):	
ID numbers (if necessary, i.e. financial benefit number [AISH ID] or insurance plans such as Blue Cross, or Handi-Bus ID number for bookings for transportation to appointments) Record all numbers you think you need to have on hand in this space Contact Information for Professionals: Include phone numbers and e-mails	
Numbers of Health Professionals. For example: physicians, community based nurses, hospital clinics, social workers, psychologists other	
Agencies who provide support workers and service for your young person	
Previous School or Program Attended (Record name of school, address, postal code and phone number) I.e. Recreation Programs	
OTHER CONTACTS	

Guardianship and trusteeship

Information about guardianship and trusteeship and how it will affect both the family and the adolescent is very useful. The Adult Guardianship and Trusteeship Act (AGTA) provides options for adults in Alberta over 18 years of age who are unable to make personal and financial decisions independently. This Act replaces the former Dependent Adults Act (DAA), and offers different services to better protect adults with disabilities. The Act addresses the current needs of Albertans by providing options and safeguards to protect vulnerable youth transitioning to adulthood. In order to fully understand the role of Guardianship and Trusteeship when making

decisions about youth transitioning to adulthood, one must first determine the individual's "capacity" for decision making.

Determining Capacity: Capacity relates to an individual's ability to make decisions, understand information related to decision making, and to recognize potential consequences of making a decision or failing to make a decision. Individuals over the age 18 are viewed as having the capacity to make decisions until proven otherwise. An adolescent's inability to communicate does not necessarily mean she does not possess the capacity to make decisions.

Challenges:

- You may have trouble determining whether the adolescent has the capacity to make decisions and if she would benefit from a guardian or trustee. A Capacity Assessment Report may be filled out in order to determine which option is more appropriate.
- Determining which decision making model will work best is sometimes difficult.
- You must balance and prioritize of issues such as housing, health care, social activities, education, vocational training, employment, legal and financial concerns, and social and recreational decisions.
- It may be difficult to engage the adult in the decision making process and make sure end decisions fit his values and beliefs, needs and abilities.

Strategies:

- In order to become a guardian or trustee, one must apply in one of two ways: Desk application (meeting with a representative of the Office of the Public Guardian (OPG), or Application by Hearing (in court).
- The Court appoints a person who is usually a family member or close friend but if they are unable to, the OPG or Office of the Public Trustee can be appointed, if determined necessary and no one else in the young person's circle of support is an option.
- The AGTA (Alberta Guardianship and Trustee Act) applies to situations where an adult

has lost capacity and does not have a personal directive or Enduring Power of Attorney. This website link to the Government of Alberta (Seniors and Community Supports) provides information on the Enduring Power of Attorney. In these circumstances, a relative or friend would have to apply to court to become the adult's co-decision maker/guardian (for personal decisions) or trustee (for financial/property decisions).

The Adult Guardianship and Trusteeship Act (AGTA) provides a wide range of decision-making options that are based on the capacity of the adolescent. It includes supported decision making, co-decision making, guardianship, specific decision making, and finally, trusteeship.

Supported Decision Making is an option for the adult who has the capacity to make his or her own decisions but would like some help. The individual can sign a form that authorizes someone they trust to be their "supporter". The supporter may be granted legal permission to access relevant information that might otherwise be protected under privacy laws. The supporter might also help the adult think through the decision-making process and communicate decisions, if necessary. A supported decision-making authorization would be helpful for capable individuals who face complex personal decisions, individuals whose first language is not English, and individuals with mild disabilities.

Co-Decision Making is a helpful option if the adult's ability to make decisions is significantly impaired but they are able to make decisions with support. With a co-decision-making order, the adult and their co-decision maker make decisions together. The adult must agree to the arrangement, as well as the person who is appointed as their co-decision maker. Co-decision making is appropriate for family and close friends of individuals with significant impairments.

Guardianship is necessary if the adult lacks the capacity to make personal decisions and does not have a personal directive or a co-decision-making order; in this case, the Court may appoint a guardian to make personal decisions on her behalf. A guardian can make personal decisions for the adult, depending upon the adult's needs. Usually, a family member or friend applies for guardianship, but if no one is willing or available, the Office of the Public Guardian can perform that role. Guardianship requires an authorization form to be filled out and submitted. There is an instruction sheet on the Government of Alberta website to assist parents in filling out the necessary forms.

Specific Decision Making is an option which may be used by health care providers (physicians, nurse practitioners or dentists for dental care only) to allow a relative to make a one-time decision on behalf of an adult who lacks capacity. Decisions are restricted to specific areas (e.g., health care treatment or temporary admission to or discharge from a residential facility).

Trusteeship is necessary if the adult lacks the capacity to make his own financial decisions; the Court may appoint a trustee. Usually, the trustee is a family member or friend, but the Office of the Public Trustee can be appointed if no one is willing or available.

This link provides access to a brochure with more information about guardianship and trusteeship for families with adolescents with disabilities who are already 18 or approaching that age: A guardianship and trusteeship self-help kit is also available on the Government of Alberta website and is useful when completing applications for either orders.

Additional questions about The Alberta Guardianship and Trusteeship Act may be directed to The Office of The Public Guardian (1-877-427-4525).

Independent Living

Planning for independent living should start long before your child is ready to move out. Although independence is important wherever possible, it is important to remember that a supportive framework that involves others in the family and community is really about interdependence. You will also need to think about financial considerations, such as establishing a Registered Disability Savings Plan (Government of Canada) and applying for Assured Income for the Severely Handicapped (AISH) (Government of Alberta). Check for similar programs in different provinces and territories.

Independent living can hold many different meanings for individuals with a disability. Living arrangements can vary from supported (full- or part-time in-home support, with or without roommates) to full independence. What these options all have in common is that they should foster the individual's right to make their own choices to the greatest degree possible. Key areas to consider include where to live, and the physical, social, emotional and financial support that is required to support the individual in living as independently as possible with dignity and respect.

What is Supported Independence?

For youth with disabilities, transitions should always take place with support. In this modern era, many young adults, upon reaching adulthood, delay moving away from home. There are several reasons for this, including financial costs associated with moving away from home, the need for family support and the costs associated with post-secondary education. It is not expected that young adults with disabilities move out of their home as young adults. This is an option and a choice that families and the young person makes at the point they feel comfortable to do so.

Families often recognize a growing need for independence as their young person moves through different stages of life into adulthood. Although this independence requires a supportive approach, achieving this is possible with solid planning. Inter-dependence implies that a support network needs to be in place. Supported independence includes involvement from family members and friends, along with professionals who work with the young person.

Challenges:

- Budgeting, paying bills, banking
- Accessing community supports
- Navigating public transportation
- Managing health care needs, i.e.. medication administration and doctor visits
- Dealing with anxiety, problems or stressful situations,
- Personal care
- Grocery shopping, meal preparation and nutrition
- Household chores, yard care or maintenance if required
- Safety, and how to handle crises/emergency including potential risks in the community

Strategies:

- Start planning early if independent living is a possibility. Begin this process by the young person's 16th birthday.
- Plan community living skills such as meal planning, writing shopping lists, housekeeping, and cooking, early and often. Children and adolescents can be involved in activities such as helping to cook dinner, cleaning up, weekly or regular chores, doing laundry. These are valuable skills for living away from home.
- Using public transportation
 - Take the bus or taxi with your child to get groceries, get to the mall or to the gym. Practice looking at schedules online to determine the appropriate bus to take, how to get to the bus stop on time, how to prepare bus fare for the trip, how to transfer buses, etc. This will help your child become more comfortable with public transportation.
- Identify and look into the supported living agencies available locally, as well as inclusive community organizations, such as the Alberta Association for Community Living.
- Contact programs for support and to inquire about program availability and suitability for your son or daughter. Add your young person's name to waiting lists if possible. If things change in the future and new directions are established, notify the agency so other names can move up the wait list.
- Carefully consider how much support your young person needs to live independently; there may be specific needs that will determine where and with whom she will be able to live.
- Ask your young adult what he wants for his living arrangements; does he want a roommate? Does he need a supportive roommate? If so, who would that be?

- Develop a long-term plan that defines the social, recreational, and career goals of your young adult to identify where additional instruction and support

Employment

Having a job is a central part of what it is to be an adult, sometimes taking up more than half our waking hours. A job can provide a sense of accomplishment and self worth, or conversely, can be a source of frustration and dissatisfaction. To avoid frustration, planning for work, also called vocational planning, should be based on the interests and abilities of the individual.

Challenges:

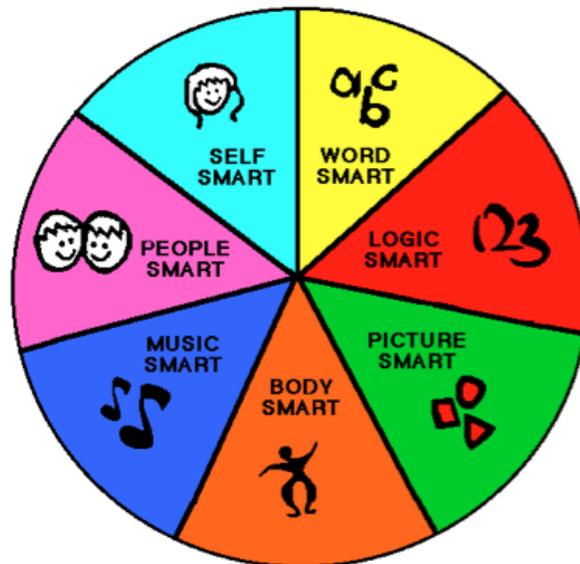
- Lack of opportunity for meaningful employment
- Insufficient supports to be able to do the job successfully

Strategies:

- Identify individual interests to ensure job satisfaction and fulfillment. For example, if an individual is interested in sports, a recreation centre may be an enjoyable atmosphere for employment.
- Define realistic expectations of job performance to ensure that an individual is not hired for a job that they cannot do. This is important so that the individual is not unintentionally set up for failure.
- Identify needs required to support the individual in the workplace. Consider the interests and individual learning style of the young person. Workplace accommodations are central to meaningful employment for people with disabilities. Examples of workplace accommodations are: workstation redesign for accessibility, reduced hours, or possible modifications related to accessibility. The learning style of the individual should reflect how information is presented to them.
- Examples of learning styles are:
 - visual,
 - auditory,
 - reading and writing, or
 - kinesthetic (hands on experience).

For more information on learning styles, consider the work of Howard Gardner of Harvard and his theories of multiple intelligences described. Gardner recognized that

people learn differently, and the beauty of his model is that there is room and respect for individual learning styles. This is important for children and young people with disabilities who may have a style that works well for them. It is important for parents and educators to perceive and understand what works best for the child and to offer opportunities suited to the learning style.



(Campbell, B., Farrow, M. & Riley, S. Retrieved online March 31, 2011 from <http://ehlt.flinders.edu.au/education/DLiT/2004/13DLT/MultIntell.htm>. Check this link for more detailed information on each learning style.)

- Establish clear communication with supervisors and coworkers regarding the nature of accommodations required. If an employment coach is involved, this can be helpful. Any decrease in workplace supports should occur in a planned and graduated fashion – fading out slowly over time as skill and confidence in the job take place. These supports are designed to support learning and gaining confidence in the workplace.

Other Options/Alternatives to Employment

I. Education

The Disability Resource Centre (DRC) at the University of Calgary exists to facilitate an accessible learning environment for undergraduate and graduate students with a disability. DRC staff, in collaboration with a student with a disability, identifies the reasonable academic accommodations that will contribute to the successful completion of their academic careers.

Their services are available to students who provide documentation of the following disabilities:

- attention deficit hyperactivity disorders
- chronic health issues
- deafness or hard of hearing impairments
- head injuries
- learning disabilities
- mental health issues
- mobility impairments
- physical disabilities
- visual impairments/blindness
- temporary impairments due to accident, illness, or injury

For more information about available services and programs at the University of Calgary, go to <http://www.ucalgary.ca/drc/>

Accessibility Services at Mount Royal University serves to facilitate reasonable academic accommodations for students with disabilities, encourage student development, and educate Mount Royal about becoming a more accessible, equitable and inclusive learning environment. For more information about available Accessibility Services and Mount Royal programs, go to <http://www.mtroyal.ca/AcademicSupport/ResourcesServices/StudentLearningServices/AccessibilityServices/>

II. Social and Recreational Programs

Social and recreational programs are beneficial for all individuals, regardless of disability. These programs offer health benefits and can help students develop friendships and learn new skills. Involvement in a recreation program is important for adults who are unable to work or attend school as this supports involvement in the community. Many programs are available for young adults and modified fee schedules also exist, relative to income. For young adults who are not employed or in school, recreation programs can offer socialization and contributes to community participation. When choosing programs, discuss

what things your young adult would like to do (i.e., go to movies, swim, learn to dance, art or theatre/drama programs). Look for programs that would best suit your child's interests and abilities. This link provides a searchable and comprehensive list of social and recreational programs across Alberta.

Alternatively, the Sinneave Family Foundation has a searchable resource database of programs and services available throughout Alberta tailored to individuals with autism, but can also be helpful for other disabilities.

Finances and Funding

Parents helping youth transition into adulthood and planning for an independent and financially secure future is often challenging; for families with a child who has disabilities, it can be even more difficult. Getting information about eligibility for financial supports as an adult should begin by age 16 and, if eligible, they should be in place for the 18th birthday in Alberta and all other provinces except B.C., where age 19 is the guideline for adult status.

To Do:

- Determine eligibility for Disability Tax Credit* (DTC) and other tax deductions.
- Look into funding** (scholarships, financial aid) for vocational, educational, etc. programs.
- Determine if your child is eligible for the Registered Disability Savings Plan.
- Determine which medical expenses are eligible for refund. Some medications and alternative treatments will no longer be covered once the youth turns 18; address this early to facilitate a smooth and successful transition into adulthood.

*Disability Tax Credits provide tax credits for persons with severe and prolonged mental or physical disabilities and their family/support persons. For Albertans who are not paying into the tax system, some but not all of their credits may be transferred to family members that provide them with care on a regular basis. The scope of tax credits available to Canadians with disabilities includes the Federal Disability Supplement, moving expenses, tuition, medical expenses, personal support fees paid to a group home, and renovations to existing property and new construction to increase accessibility.

** Assured Income for the Severely Handicapped (AISH) provides financial assistance to adult Albertans who have a permanent disability which impairs their ability to financially provide for their own well-being. Eligibility for AISH depends on the individual having a severe handicap that causes a substantial limitation in the individual's ability to participate in the labour force. Albertans receiving AISH have access to medical supports, including Alberta Health Insurance and the Alberta Medical Services Card (covers optical, dental, prescription, ambulance services, and other health-related needs). Prior to the completion of an AISH application, Albertans are required by AISH policy to apply for Canada Pension Plan disability benefits. For more information, go to <http://www.seniors.alberta.ca/aish/>.

The AISH Benefits Administration Program provides additional funding to individuals receiving AISH for personal expenses such as special dietary foods, transportation to medical appointments and costs of school-related expenses for dependent children. It delivers health benefits to individuals receiving AISH benefits, their spouse and dependents. Benefits include premium-free Alberta Health Care insurance, prescription and limited non-prescription medication, emergency ambulance coverage, dental and optical care, essential diabetic supplies and the waiver of Alberta Aids to Daily Living co-pay fees. For more information, please go to http://justice.alberta.ca/programs_services/public_trustee/aish/Pages/default.aspx.

Alberta Aids to Daily Living (AADL) program helps Albertans with a long-term disability, chronic illness or terminal illness to maintain their independence at home, in lodges or group homes by providing financial assistance to buy medical equipment and supplies. An

assessment by a health care professional determines the equipment and supplies that an Albertan can receive through this program. For more information, go to <http://www.seniors.alberta.ca/aadl/>.

Residential Access Modification Program (RAMP) is a program available to eligible wheelchair users to modify their home to be more wheelchair accessible. Applicants can apply for a RAMP grant for up to \$5,000. For more information, go to <http://www.seniors.alberta.ca/aadl/ramp/>.

Persons with Developmental Disabilities (PDD) is a provincial government program that provides funding for staff supports for adult Albertans with developmental disabilities. The PDD Program works with others to support adults with developmental disabilities to be included in community life and be as independent as possible. Funding is provided to support individuals in their home, work and social environments based on individual need. These services supplement the support of family, friends and community members and assist the individual to live as independently as they can in the community. The PDD Program funds four categories of services: (1) Community Living Supports provides assistance to individuals in their home environment; (2) Employment Supports train, educate and support individuals to gain and maintain paid employment; (3) Community Access Supports promote community access and participation; and, (4) Specialized Community Supports are generally short-term supports provided in unique circumstances. The application process must be started before the individual is 18 and he or she must have an IQ below 70. For more information, go to <http://www.calgary-pdd.org/dnn/bHomeb/tabid/36/Default.aspx> (For the Calgary PDD Board).

Alberta Advanced Education and Technology has developed several resources to help students with disabilities make the important transition from high school to post-secondary education or training. There are also numerous scholarships, grants and apprenticeship opportunities for adults. For access to these resources and programs, go to <http://www.advancededucation.gov.ab.ca/planning/assistance/transitions.aspx>.

Disability Related Employment Support (DRES) Program is part of the Alberta Immigration and Employment Program and funds supports and/or services to help Albertans with disabilities make successful transitions from school to work, unemployment to employment and from one career path to another. DRES is grouped into three categories according to the nature of the Service Plan item that the person with a disability is engaged in at the time he or she accesses the supports and/or services: (1) Job Search Supports; (2) Workplace Supports; or (3) Education Supports.

Alberta Health provides reproduction and sexual health services for all Albertans; services include sexual education and birth control centres. Mental health, homecare, and rehabilitation services are also available through Alberta Health. For more information on available services and programs, follow this link to Growing Up Healthy on the Government of Alberta Health and Wellness website. There are multiple links on this site related to Healthy eating and active living; Growth and development; Dental care; Immunizations; Injury prevention, Health education; Adolescence and Puberty and sexuality.

Office of the Public Trustee (OPT) of Alberta protects the financial interests of vulnerable Albertans by administering the estates of represented adults, deceased persons and minors when there is no one else to act. The type of assistance that may be provided to a person with a cognitive disability will depend on the nature of the disability, the type of property owned and the availability of those prepared to assist the disabled person. The OPT provides more information on the different options for assistance and services available.

Office of the Public Guardian (OPG) provides decision-making mechanisms for individuals who are unable to make personal, non-financial decisions for themselves. The legislation guiding the policy and practice of the OPG includes the Personal Directives Act, the Adult Guardianship and Trusteeship Act and the Mental Health Act.

Unit 3

Developmental Transitions

Introduction

For all teens, the process of moving from childhood to adulthood is challenging. For young people with disabilities, transitioning to independence presents even more challenges. There are many barriers to successful transition for young people with disabilities: low expectations by people in the community; lack of self-advocacy skills; lack of transition services and supports in the community; lack of awareness and understanding of disabilities in general in the community. It is important to determine your child's strengths and passions and develop achievable expectations for skill development, attitudes, and behaviours that will promote self-sufficiency in adulthood.

Effective management of transitions requires open and effective communication between the youth, parents and professionals. Active parental involvement is essential for

understanding unique and child-specific characteristics that pose challenges. Preparation, education and communication are the keys to successful transitions.

This section reviews the following topics: Puberty, Sexuality/Sexual Development and Relationships.



Puberty

Challenges:

The transition to puberty can be challenging for many children and their parents. It is common for children with neurodevelopmental disabilities (e.g., cerebral palsy, autism, Fetal Alcohol Spectrum Disorder) to transition into puberty early. Early onset of puberty can further challenge children with disabilities, who may be socially immature, by: affecting an already altered body image and self-esteem; increasing the complexity of self-care and hygiene activities; and heightening the risk of sexual exploitation.

Strategies:

- It is beneficial for you to be the principal teacher of developmentally appropriate sexual education for your child, incorporating family values, cultural traditions, and religious beliefs.
- Discuss issues of physical development, maturity and sexuality on a regular basis, starting in early childhood and continuing through early adolescence so that you and your child are comfortable having these types of conversations.
- Encourage the use of proper terminology of body parts, and discuss the differences between male and female parts. Explain the difference between “good and bad touch”. Pictures can be helpful here to aid in the child’s understanding.
- Discuss the difference between public and private places (e.g., bathroom vs. classroom). Pictures can also be helpful here.
- Educate your child about hygiene and self-care; autonomy in this area will be based on your child’s individual abilities. Children should be involved in hygiene from an early age.
- Open a dialogue with your child so that he feels free to express himself and discuss his feelings in a safe environment free of judgment.

Sexuality/Sexual Development

Sexual development is a complex process, closely linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings. It not only involves anatomic and physiologic func-

tioning, but it also relates to sexual knowledge, beliefs, attitudes, and values. Sexuality should be considered in a context that extends beyond sexual behaviour to include gender-role socialization, physical maturation and body image, social relationships, and future social

aspirations. Like all adolescents, teens with disabilities may express desires and hopes for marriage, children, and normal adult sex lives.

Parents face many challenges when preparing their child for the coming of adulthood. Providing sexuality education to young people with disabilities is a particularly important but often a difficult task. For people with disabilities, there are many obstacles to healthy sexuality. The desire to keep them safe also unintentionally keeps them dangerously in the dark. Furthermore, they are vulnerable to societal myths and misconceptions, are taught to be compliant to authority, and are at higher risk for sexual abuse.

Human sexuality education for young people with disabilities has significant benefits. These benefits include, but are not limited

to, improved social skills, assertiveness and independence, positive changes in behaviour (e.g., adopting more appropriate expressions of sexuality), and reduced risk of sexual abuse, sexually transmitted diseases and unintended pregnancy. Unfortunately, young people with disabilities often do not acquire sufficient knowledge regarding sexuality and, even though sexuality is a universal human trait, sexual expression in this population can provoke strong negative reactions.

Cultural, ethical, religious, and moral issues influence sexuality, and as such, prescribed sex education is controversial. Parents, educators and young people may find themselves at odds over information and attitudes they consider appropriate.

Challenges:

- People with disabilities are often regarded as childlike, asexual, and in need of protection. Conversely, they may be viewed as inappropriately sexual or as having uncontrollable urges.
- Many adolescents with disabilities receive inadequate information regarding sexuality or do not understand the information presented.
- It may be difficult to teach personal care related to menses.

Strategies:

- Review available educational materials to promote successful sexuality education.
- Modify sexual education programs and materials to allow the information to be presented in such a way that your child can understand it. Modifications such as simplifying information and using special teaching materials may be required.
- Individualized program plans (IPPs) should include the provision of sexuality education for children with disabilities.
 - Appropriate educational programs for young people with disabilities include the following topics: body parts, puberty, personal care and hygiene, medical examinations, social skills, sexual expression, safe sex, and the rights and responsibilities of sexual behaviour.

Relationships

Humans are social creatures. Our sense of who we are and our place in the world is constantly being defined for us by the quality of our social contexts: inclusion in community, our friendships, being valued and loved, social connections in school and work, and our sense of whether people seem glad to see

us, and want us around. Individuals with significant deficits in communication find it even more difficult to create and maintain healthy relationships. Development of social skills requires early intervention and the provision of guided learning opportunities.

Challenges:

- Societal attitudes and stigmas around people with disabilities
- Difficulty understanding facial expressions, and reading body language
- Initiating conversations with strangers and peers
- Finding inclusive settings that provide the opportunity to meet new people and make friends
- Fear of rejection

Strategies:

- Take an active role in the community to increase awareness of people with disabilities.
- Use social skill building exercises (i.e., social stories, role play) that demonstrate and teach about healthy relationships.
- Seek out inclusive education programs that reflect the child's interests and encourage positive interactions with peers.
- Enroll children in social and recreational programs outside of school that help to build friendships and social networks.



Unit 4

Medical Transitions

Do not go where the path may lead, go instead where there is no path and leave a trail.

-Ralph Waldo Emerson

Introduction

Parents of children with disabilities, concurrent health conditions and serious medical problems have to consider added transitions at different ages and stages of life. Children who have a developmental disability and serious medical issues are often identified as medically fragile or medically complex. The term medically complex will be used in this module. Children with these challenges often have progressive (deteriorating), life threatening, medical conditions that have to be carefully monitored by families, physicians and clinical teams. For some children their physical disabilities often lead to deteriorating health conditions in adulthood.

Children with disabilities who are medically complex are living longer lives today due to advances in health care and the excel-

lent physical care, nurturing and stimulation they receive from their families and caregivers. When everything is new it is often difficult to cope, but over time the different experience of having a child who is medically complex becomes familiar. Families learn to expect the unexpected and to work around the circumstances, discovering what works best for their child and family. Children who receive love and care that is designed around their unique needs often thrive.

Complex medical conditions can involve multiple systems, which can change in status over time. While attending to the medical needs of the child, parents also have to deal with the process of accepting new information about a challenging medical condition. The family is experiencing a process of grief, loss

and adjustment at the same time. Some children qualify for care from pediatric palliative care programs, which may also offer respite care for children with complex conditions. Most children can be followed in the community, maintaining contact with their medical care team either during clinic visits or hospitalizations. Some children require frequent hospitalization due to their illness, and constant supervision due to their disabilities. The concept of 24/7 care is embedded in the lives of families living with a medically complex child.

Child and family wellness are difficult to consider as separate as they are intricately interwoven. Parents who have a child who is medically complex want to provide a good quality of life for their child but require the support of medical professionals in relation to guidance and knowledge about the condition. Parents also want to know what to expect, in regard to the impact of their child's medical problems over time. Parents do not want to see their child in pain, as this is stressful for both

children and parents. With advancements in medical care, health care professionals have developed many techniques to deal with the pain and stress associated with medical tests and chronic medical conditions. Families need to have discussions with their medical team about the most effective way to respond to these concerns.

There is a great deal of stress associated with ongoing medical care for a child, and medical intervention can sometimes feel intrusive to a family. Life can be challenging to manage when frequent medical intervention is required. Families develop their own strategies for coping and it is important to recognize that this is a learning process that will have ups and downs. Many parents struggle with their own sense of well-being when their child has a medical setback or downturn of health. When your child is doing well, life feels manageable. When your child is not doing well, it means drawing on resources and available supports to get through those challenging times.

The Culture of Families with Medically Complex Children: The Metaphor of a Pathway

Families with children who are medically fragile often find themselves walking a pathway that can go in any direction at a moment's notice. Parents and siblings experience the ups and downs along with the child who has serious medical issues. There is a pattern of adjustment that occurs on a regular basis in response to medical problems and plans frequently need to be altered. Accepting change becomes part of the culture of a family, and

the ability to adapt demonstrates both strength and resiliency. It is important to recognize the impact of these situations on siblings and extended family. Worry and concern over the medically complex child can lead to overlooking the needs of other family members. This is not intentional, but can lead to difficulties in family relationships.

Transitioning from a Children’s Health Care System to the Adult Health Care System

“Youth with chronic health conditions face two simultaneous transitions: a developmental transition (from childhood to adolescence to adulthood) and a situational transition (from pediatric to adult health care)... The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound prior to and throughout transfer into the adult system.”
(*Contemporary Pediatrics, A Canadian Journal Dedicated to the Care of Children [1998] p. 15*)

Moving from a child-focused health care approach to an adult-focused system is often a stressful experience for families. There are many reasons for this. As a child with major health issues grows older, relationships with medical professionals and caregivers within that system grow stronger over time. When you parent a child with serious medical challenges you come to rely on the support,

wisdom and guidance of the team that has grown around your child. It seems when your child is young that a move to the adult system is far away. However, as the teenage years progress, parents and professionals both begin to think about what a transition to adulthood means in relation to services and supports.

One of the major concerns of family members is how the child will adjust to the transition to adulthood. Common questions that family members may have include:

1. How will my child adjust to new doctors and nurses?
2. What will it be like for my child to be cared for in an adult hospital?
3. How will the 24/7 care, and supervision needs of my child be met in an adult system?
4. What supports exist in the adult system for our family?
5. How will my child emotionally handle such a major change?

The response to these questions will be different for each family. It is important to know that a shift to the adult health care system, although different, is a natural progression.

Family members of children who are medically complex are usually very involved in their child’s health care and this involve-

ment carries on into adult life. Different needs emerge over time as children grow into young adults and become involved with systems for adults with disabilities.

Roles and Responsibilities

It is important to clarify roles and responsibilities for family and professionals related to the transition to adulthood. As a family, you have a primary role in communicating your needs during this process. The medical team and primary physician for your child have a role in advising you about what to

expect. A protocol will exist within each medical clinic to facilitate the transition to adult services. Generally, a meeting will be held with the family and members of the medical team to begin this process and further meetings may be required.

Natural Supports

Child and family wellness are difficult to consider as separate as they are intricately interwoven. Extended family and/or friends can be a major source of support through the many changes you face. When you meet with medical professionals, it can be helpful to have at least one family member or a close friend present who can offer support and with whom you can talk about the information presented following the meeting. Some families prefer to have meetings with medical professionals on their own. Taking notes is always a good idea as a great deal of information is often exchanged in these meetings. Alternatively,

you might request that the medical professionals provide their suggestions in writing so that you can discuss it later with people who are supportive to you. It is important for you to consider your own style in working with the medical professionals caring for your child. Figuring out the approach that works best for you will take time. Some children have a primary caregiver for a variety of reasons, including parents who are working and not always available to take their child to medical appointments. It can be helpful to involve the primary caregiver in discussions related to transition.

As your child grows older you will become more confident in discussions and meetings with the medical system. Some medical institutions offer a parent-to-parent support program where parents who have had experience with a particular disability or medical condition agree to offer support to a family who may have a new diagnosis. These types of connections may be established through social work or clinic staff nurses. It is important to remember that each family will have a unique approach to working through the stresses and uncertainties that face them.



Important Issues to Think About in Relation to Medically Complex Children Moving to Adult Services

Often multiple transitions occur at the same time as the transition to the adult health care system. Young adults finish high school and new life goals need to be set. The physical care needs of a medically complex child may be compounded by several factors. As a child grows, the ability of parents (who are also

growing older) to provide physical care may change. There may need to be adaptations to the physical environment and additional supports in the home to assist with physical care. Parents may need more respite as demands increase.

Planning - Change is a challenge, but it can be managed with a clear planning process that begins by the age of 16 or sooner. Establish a transition plan early in order to manage the process. Identify the tasks that need to occur, identify the person responsible, establish a timeline and begin the process.

Transition checklists - Create checklists for all the items in your transition plan. A checklist will help you to keep track of persons you have to contact, phone numbers, e-mails, fax numbers as well as keeping track of dates of contact. A checklist forms a record of the calls you have made, which is helpful when you have to follow-up on requests for information, appointments and meetings.

Asking for help - Remember that professionals in the health care system for children have experience with transitioning medically complex children and can offer support in this process. Ask your current medical team for referrals to medical professionals and specialists that work within the health care system for adults. Having a medical letter available that explains your child's medical condition can often be helpful when a visit to the Emergency Department of an adult hospital is required.

Develop new supports - Families can request supports from helping professionals, such as social workers or psychologists working within the adult health care system, to assist with the transition. If you believe you need this support, ask your current team for a referral. Alternately, ask if you can make contact yourself.

Communication - Stay in regular contact with the professionals supporting the transition to adult services. Communicate with family members and friends about this process as it moves along.

Allow yourself to grieve - Recognize that you will experience some sense of loss about the relationships you have with your child's medical team. Given your reliance on this team over the years, grief related to change is part of the process.

Acceptance - Accepting that adult services are different is an important part of the transition. Services that are child centred are different from those that are adult centred and this is simply a reality. This does not mean that your child will not receive the same quality of care. It does mean however that the environment and culture of adult care is different and will require adjustments from you, your child and your family.

Adaptability – Parents and caregivers are accustomed to change. Recognize that the adult health care system will not be as familiar with your young adult. You have an opportunity to educate professionals in the adult system about the distinct care needs for your child. It is a learning process for everyone. As you came to rely on the team for your child, you will also come to rely on a new team of professionals for your young adult.

Be prepared - It is helpful to have documentation related to decisions about medical intervention in life and death circumstances. Parents of medically complex children often address these concerns over the years and make decisions about care and interventions under these circumstances. Ask for the support you need in relation to making these types of decisions.

Flexibility - Change is part of the landscape for parents and caregivers of children who are medically complex. Keep in mind that being flexible will help you through the process. For example, a meeting related to the transition may be called on short notice, or may need to be changed, due to emergency situations in the medical system. Remember that you have no control over this and need to work around these issues.

Coping strategies - Identify what helps you cope with the stress of change. Reflect on what you need to work your way through this process. The transition to adulthood takes time, patience and perseverance.

References and Resources:

Canadian Websites Related to Medical Transitions

The Family & Community Resource Centre
<http://fcrc.albertahealthservices.ca/>

Alberta Children and Youth Initiative
<http://www.seniors.alberta.ca/disabilitysupports/documents/TransitionPlanningProtocol.pdf>

Children's Link Transition Manual
http://www.childrenslink.ca/pdf/templates/transition_manual.pdf

BC Children's Hospital

<http://www.aboutkidshealth.ca/BCCH/EN/ResourceCentres/Pages/default.aspx>

Canuck Place - Vancouver

http://www.canuckplace.org/family_kids_corner/resources_support/financial_and_medical_benefits.php

Children with Intellectual Disability – BC ACL

<http://www.cw.bc.ca/library/pdf/pamphlets/SH16.pdf>

Transitions for Youth with Disabilities – BC

http://www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf

Positioning and mobility: Transitioning to adult services -- Vancouver, BC: Sunny Hill Health Centre for Children, 2009. (Pamphlet) - BCCH1560

<http://www.cw.bc.ca/library/pdf/pamphlets/PositioningMobilityTransition2009Read.pdf>

CanChild Centre for Childhood Disability Research – McMaster University

<http://www.canchild.ca/en/ourresearch/priorities.asp>

Youth Transition – YouTube plus other resources

http://www.canchild.ca/en/canchildresources/youth_kit.asp

Articles link

http://www.canchild.ca/en/ourresearch/articles.asp?_mid_=2458

Persons with Disabilities Online

<http://www.pwd-online.gc.ca/pwdh.4m.2@.jsp?lang=eng>

Health Care Transitions

http://hctransitions.ichp.ufl.edu/products_planning_guides.php

http://hctransitions.ichp.ufl.edu/pdfs/HCT_Workbook_18up.pdf

Transitions to Adulthood for Youth and Children with Disabilities (2008) Canadian

<http://cirrie.buffalo.edu/encyclopedia/en/article/110/>

Transitions to Adulthood – University of Alberta

<http://www.rehabmed.ualberta.ca/transitions/>

American Websites

Ability Online Community for Youth with Disabilities

<http://www.ablelink.org/public/new/index.html>

- American but great material
- Includes siblings for family wellness project

<http://www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know>

Cincinnati Children's *We need a Canadian version of this site – all the links below are part of this site.

<http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/transitions.htm>

<http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/get-started.htm>

Parent Handbook

<http://www.cincinnatichildrens.org/assets/0/78/1067/1395/1957/1959/578174fc-6872-4b7a-9a64-03a6ff6f88d5.pdf>

All About Me Form

<http://www.cincinnatichildrens.org/assets/0/78/1067/1395/1957/b2ea7ed3-d099-4fe0-8597-590b9e58f690.pdf>

I am the child poem

<http://www.oafccd.com/lanark/poems/child1.htm>

New Journal Article

Parenting Children With Disabilities: Navigating Through the Storms Journal of Creativity in Mental Health

Volume 5, Issue 1, 2010, Pages 87 - 92

Author: Margaret Costantino [show biography]

DOI: 10.1080/15401381003627335



Unit 5

Life Transitions

Introduction

Life includes many transitions. Some can be prepared for and are positive experiences, such as a new sibling or moving. Others are not planned and may not be positive, such as divorce and the death of a loved one. No matter what the circumstances are, it is important that all children and youth receive the information and support that they need in order to make transitions easier. Sometimes as adults, it is challenging to know what to say to young children when something bad happens, so often parents will say nothing. This may have negative consequences and it is often best to try to find a way to explain change and transition to children. Early learning educators, teachers and team members may be able to assist.

Children with developmental delays and disabilities may have less capacity to understand these transitions and cope with them. Children will experience transitions differently based on their age, maturity, temperament and ability. Children often have less time to prepare for transitions, as well as fewer skills to cope with them, so they are more vulnerable than adults. Parents and caregivers, with support from teachers, health practitioners and community resources, can make transitions easier for children to cope and adjust through these periods of change. Some children may not adjust as well as others and may need professional help. If your child has continued anxiety, depressive mood, or problems with sleeping or eating for a prolonged period of time, you should consult your child's physician or pediatrician.

Divorce

Divorce is a transition that is experienced by many families in Canada. Having a child with a disability can be very stressful for parents and may add strain to a marriage.

Divorce can be considered as several transitions, which may include moving to a new home or neighbourhood, living with one

or both parents on a rotating schedule and the introduction of step-parents and/or step-siblings. These transitions are difficult for any child to experience and can impact children differently depending on their developmental stage.

Challenges:

- The experience of parental conflict can be stressful for a child
- Adjusting to the routine of a new custody arrangement between parents
- Possibly moving to a new home and loss of pets, friends, school
- Introduction of new family members, including step-parents or step-siblings
- Potential loss of family members such as grandparents

Strategies:

- Protect your children from exposure to marital conflict.
- Keep as many routines and surroundings intact as possible - many transitions at once are much harder to cope with than one or two at a time.
- Give your child lots of physical presence and support.
- Give your child as much information as possible – let her know that she is not responsible and is loved and will be cared for.
- Talk with your child about how the changes are making him feel.
- Keep your expectations appropriate to her developmental level. For example, do not ask young children to pick up extra household chores unless developmentally appropriate.

Loss

The loss of a loved one through death or other separation is a difficult transition for children because they may not be able to understand what death means or that their loved one is not returning. Sudden death or loss can be especially difficult to deal with because the child is less prepared for the transition. The

grieving process for children involves coming to an understanding of the loss, and then coping without the loved one. This can be an ongoing process, as the child may need to reprocess the loss as they develop, and their understanding of death matures.

Challenges:

- The child's stage of cognitive development will impact how he thinks about death. Children may understand loss in different ways and say funny or distressing things. It is important to remember the development of the child in explaining death.
- Children may grieve in different ways. For example, they may be sad for short periods of time and then seem fine.
- Children often use play as a way of understanding death. For example, some children will play "funeral". This is normal, and reflects a child's efforts to make sense of what happened.
- Parents may underestimate a child's experience of loss because of their own experience with grief or because the child does not appear to be grieving.
- When children are distressed, they are less able to process complex and abstract information.

Strategies:

- Talk to your child about what he is thinking and feeling about the loss.
- Share your own feelings.
- Be patient and prepared to repeat yourself when trying to help your child understand the loss.
- Find ways for the child to cope. Helping them make a memory or scrapbook can be helpful.

Moving

Moving into a new home can be one of the most stressful experiences in a person's life. Moving, whether it is to a new home, neighbourhood or city can be especially stressful for families of children with disabilities. A move can entail multiple losses: familiar surroundings, routines, supports, friends, and school.

It may also require an introduction to new surroundings, people, routines, schools, service providers and support systems. Children with disabilities may find these changes overwhelming and difficult to adjust to.

Challenges:

- Children may be stressed with the loss of familiar surroundings and friends.
- The introduction of new routines can be difficult to adjust to.
- Children may have difficulty understanding why they have to leave their home.

Strategies:

- Provide consistency in routines as much as possible.
- Be physically and emotionally available to your child.
- Access new community services and neighbourhood supports.
- Provide children with productive outlets such as arts and crafts, physical activity, music and pretend play.
- Keep connections with friends and family.

A New Baby in the Family

A new addition to the family is an exciting time, but can also present challenges. The addition of a new sibling can be difficult for children to adjust to, and jealousy is a common reaction. Children may be worried about getting less attention or being replaced. Children with developmental delay or disability

may have more difficulty understanding and adjusting to a new sibling. Parents and family members can take steps to reassure children and help them build a relationship with their new sibling.

Challenges:

- Children may feel jealous or resentful towards the new baby.
- It can take time for a child to sort out their feelings towards a new baby.
- Other changes in routine or household such as moving bedrooms for a new baby can be stressful.
- Caring for a new baby takes time, which may mean that parents have less time to spend with older siblings.

Strategies:

- Start preparing your child for the new baby during the pregnancy, particularly when the mother starts to show her pregnancy.
- Involve your child in preparation for the new baby, such as decorating the baby room.
- As the due date arrives, explain to your child that mom and dad will be going away for a couple days, and try to keep as much of his routine intact during the birth.
- Once the new baby arrives, be patient and give older siblings time to meet the new baby.
- Supervise closely to keep the baby safe.
- Encourage your child to talk about what she is feeling towards the new baby.
- Try to set aside some time for just yourself and the older sibling every day.

7

Module 7: Family Challenges & Wellness

Unit 1: Introduction and Overview

- Topic 1:** Introduction
- Topic 2:** Awareness of development delays leads to questions from families
- Topic 3:** Focus on diagnosis, grief and loss
- Topic 4:** Grief, joys and loss in a family living with childhood disabilities
- Topic 5:** Grief and loss/Adjustment to diagnosis

Unit 2: The Family

- Topic 1:** Nurturing your partner/ Marital relationships
- Topic 2:** Siblings
- Topic 3:** Extended family
- Topic 4:** Foster family
- Topic 5:** Adoptive family

Unit 3: Special Considerations

- Topic 1:** Working parents
- Topic 2:** Single parents

Unit 4: Family Wellness

- Topic 1:** Developing natural supports
- Topic 2:** Self-care
- Topic 3:** Time

Unit 5: Encouraging Social Skills Development and Friendships

- Topic 1:** Supporting your child's friendships
- Topic 2:** Parent roundtable

Unit 1

Introduction and Overview

Introduction

The focus of this module is family issues and wellness. This is an important topic for parents of children with disabilities. Every child with a disability comes from a family. The family is the most important place for children with disabilities. It is within the family that both the child and family learn to live with a disability. All children are dependent on their parents for love, nurturing, care, guidance and support. For the child with a disability, these needs are the same and more. Parents

have to learn about what it means to be the parent of a child with a disability. Parents also need to learn about the disabling condition, medical/health care issues, developmental concerns, educational issues, behavioural management strategies and how to connect with service systems that support the child and family. Families must learn to adapt to meet the unique needs of their child with a disability in the context of their family structure.

In consideration of the family structure, this module introduces six units with specific topics related to family concerns. The six units are:

- 1) Diagnosis, Grief and Adjustment
- 2) The Family
- 3) Considerations for Single Parents and Working Parents
- 4) Relationships with Aides, Caregivers and Workers
- 5) Family Wellness and Self-Care
- 6) Encouraging Social Skill Development and Friendships

Within each of these units, specific topics are identified that are relevant to the unit, offering greater detail for family members. The purpose of highlighting each of these topics in depth is to offer information that is helpful to families raising a child with a disability. It is hoped that offering this information and insight from both a parent and professional perspective will be of help to families living this experience.

Each family is unique. Within the family, everyone learns and grows together in understanding and developing meaning about the experience of raising a child with a disability. More often than not, there is no indication prior to birth that the child has a disability. It is important to know that, when a child with a disability becomes part of a family, there is an adjustment period for everyone – including parents, siblings, grandparents and other family members. For this reason, the focus of Unit 1 is about diagnosis, grief, and loss issues.

Most children who are born with a disability stay with their families, and parents, siblings and extended family work together to support the child with unique developmental needs. Other children, who for one reason or another cannot be cared for by their family of origin, may be placed in foster care or adoption. The focus of Unit 2 is on the family and includes important issues about relationships in immediate, extended, foster and adoptive families.



Each family has its own structure and considerations unique to that family. An important consideration for the family of a child with a disability is work. Work is important for both income and health care plans/benefits. In the case of a single parent who must work to support their family, child care is essential for preschool children. Sometimes marital/partner relationships break down due to family stress and/or relationship problems, leaving one parent to raise the child/children alone. Being a single parent of a child with a disability is challenging. The focus of Unit 3 is on special considerations for working parents and the single parent.

When you are the parent of a child with a disability, at some point you will likely need the care and support of others from outside the family. When required, programs that provide aides, support workers or other types of caregivers are important resources for families. When having a caregiver work with your child, it is important to think about communication with the agency, the aide or caregiver. The focus of Unit 4 is on those caregiving relationships, providing feedback, managing conflict and problem solving.

Family wellness is dependent on the health and wellbeing of the parent(s) as primary caregivers. It is particularly important for parents of children with disabilities to know their strengths and limitations. The focus of Unit 4 is on family wellness and related topics, including developing support systems, self-care, time management and the use of respite.

Every child needs their own network of friends and others outside the family who become part of their circle of support. You have a role in developing and encouraging friendships when you are a parent of a child with a disability. Children learn to develop natural relationships within their family and this often extends to the community. If developing relationships outside the family is a

concern, parents and siblings have an important role in creating opportunities for this to occur. A child's circle always expands beyond the family, when they enter day care, preschool programs, school and other activities such as recreation. The focus of Unit 5 is on encouraging social skill development and friendships.

The information contained within this module on Family Wellness is intended for all families who care for and include a child with

a disability as a family member. Parents often need to become advocates for their child to ensure he or she is included in the community. A child with a disability wants to be included in all dimensions of family life, inside and outside the home. It is important to remember that each family is unique and has its own approach to best meet the needs of their sons and daughters.

It is important for families to find a way to live with all the challenges and joys this experience provides. What does family wellness mean when you have a child with a disability?

- Acknowledgement of grief and loss issues associated with childhood disability
- Acceptance of the unique needs and demands of the child with a disability in a family
- Recognition that there are social/emotional, physical and spiritual dimensions in this experience
- Maintaining a positive attitude even when things seem too difficult to manage
- Learning to ask for help when it is needed
- Finding a balance that works for all members of the family
- Negotiating roles and responsibilities of each family member
- Engagement in open communication that considers the needs of each family member
- Developing problem-solving strategies within the family
- Developing problem-solving strategies for working with professionals
- Awareness that adjustment to change will be a part of family life when working with professionals from outside the family
- Recognition that organization, scheduling and time management are important because children with disabilities do best with structure and routine
- Recognition that as a family you will adjust, find a balance and a way to move forward with life

Awareness of developmental delays leads to questions from families

What happens when you, as a parent, begin to worry that your child is not developing as expected, not ‘keeping up’ with your friends’ children that are the same age? Initially, parents often believe that the child will develop skills but it’s just taking a bit longer. When it becomes clear that there is a developmental delay, parents often speak to a family physician and may be referred to a developmental pediatrician for assessment. It is important at this time to seek guidance from the health professionals you are working with.

Not all disabilities are diagnosed in early childhood. Do not become discouraged! Accept the referrals you are given for support

with developmental concerns, such as testing, therapy and counseling. Work with the professionals, get support from family and friends and just start going down the road – it is a journey.



Focus on diagnosis and grief and loss issues

Diagnosis is about naming the disability. Sometimes disabling conditions can be identified and other times they cannot, despite the best efforts of medical professionals. Some children are identified as having developmental disabilities and the cause is never discovered. It is important for parents not to blame themselves for causing a disability. There is a chance in all families that a child can be born with a disability. This is simply a reality. What is important about getting a diagnosis is that this information will help families to have an understanding of their child’s needs. Having a diagnosis can also help to identify supports that are required to meet the developmental needs of the child.

If a child is born with a disability that is evident, such as Down Syndrome or other

disabilities identified through early screening after birth, parents are informed by health professionals about issues related to child development, medical needs and interventions. The information and referrals provided by health professionals at the outset are critical resources. It is quite natural as a parent to feel overwhelmed at the early diagnosis of a disability. In situations where prenatal screening was done and evidence presented that the child has a health condition, parents may feel somewhat prepared for how to handle a child who will be born with a disability. For most parents, this is not the case and diagnosis of a disability at birth comes as a surprise. The initial response of most parents is shock at this unanticipated experience. It is a major adjustment becoming a parent of a child with a dis-

ability and one you must grow into. It does not happen overnight and a sense of grief and loss is not uncommon.

After a diagnosis, early questions include concerns about the cause of the disability. Sometimes there is no answer to this question. Parents sometimes blame themselves when, in fact, there is nothing that could have been done to change the outcome. It is important not to blame yourself, and to begin to gather information that you will need in terms of the particular disability, available resources such as support groups, and establishing contact with the health professionals that will help guide you through the process. Asking for help is essential. One resource that can be requested is professional counseling. A social worker, psychologist or developmental specialist in early childhood can be made available to you. If this is not offered to you, make sure to ask for a referral. Parents do not need to go on this journey alone. There are so many things that go through a parent's mind besides wondering why this happened. Concerns extend to explaining things to family and friends, won-

dering how to cope and what you will need to do so. These are all reasonable concerns and it is important to work with someone who understands the journey you are undertaking and can guide you, particularly in this early stage as a new parent of a child with a disability.

The process of getting a diagnosis can occur immediately after birth or at any time during the developmental years. When families become aware that there is a problem, they begin seeking answers. They go to doctors, and often get referrals for specialists such as a pediatrician or possibly a developmental clinic. When it is determined that indeed there is a developmental delay, children are often referred for a variety of tests that will help determine the cause of the problems. When children are referred to a clinic for developmental testing, there are multiple ways in which assessment for the purpose of diagnosis takes place.

Testimonial

When my son was born, I knew immediately that he was going to be different from our two other children. Nothing was said by either my husband or myself, but we both had the same feeling. When we raised concerns with our family doctor, we were told, "Your son's only problem is that he has two older brothers for you to compare him to."

At five months of age, we took our son to a developmental pediatrician. He examined our son for a long time in silence, then sat down and took a deep breath. Very gently and quietly, he told us that we did have reason to be concerned. We left his office with a referral to what was then called Preschool Treatment Services at Alberta Children's Hospital, a long list of follow up appointments and a requisition for a multitude of tests.

I didn't cry until we got home. My mother in law met us at the door and asked, "What did the doctor say?"

With tears running down my face, I said, "I really thought that he would tell us that everything was going to be OK. He didn't say that."

- Brenda

The process of diagnostic testing can be very stressful for families. It is often a time of worry as parents take their children for testing. Testing for developmental delays in early childhood can involve a range of professionals including medical doctors, psychologists, social workers, physical therapists, speech therapists, nutritionists, and occupational therapists. Many of these professionals work together in assessment teams and each may have a role in the diagnostic process. Testing is often a lengthy process and requires patience. Some tests can take extended periods of time to get results and reports. Sometimes families are asked to keep track of concerns at home, such as food records if there is a problem with eating, or sleep records if this is a concern. Once testing is completed, the doctor and/or team members meet with the family to discuss the results. It is important to bring a support person with you to these meetings. Bring a pen and notebook to write down information in these meetings. These notes may help you to remember important points from meetings as questions often come up later.

It is important to know that understanding a diagnosis is a process that occurs over time. Getting a diagnosis is an important process as parents try to figure out the best way to help their child. Even though this process has its challenges, it is important for a family to gain as much knowledge as possible about how to meet the unique needs of their child. When a diagnosis of a disability is initially given to parents, this can be a very intense and sometimes overwhelming experience. As a parent learns from doctors and diagnostic team members about their child's

disability, medical conditions and what to expect as their child develops, many questions come up. What does this mean? How will the disability be monitored? What supports does my child need? Is there anyone I can talk to about this? Receiving a diagnosis of a disability is a significant life event for parents. Although this information provides challenges, it also provides answers. Once parents receive a diagnosis they begin the process of adapting to becoming a parent of a child with a disability.



Testimonial

Autism: Our Diagnosis

I remember, vividly, when I heard the word “autism” enter my life. My son (I was 7 months pregnant with my daughter) was 2 1/2 years old. Still working, I was pinched for time and needed to drop my son off at a well-respected day home for 2 hours. At pick-up time, the day home lady began apologizing profusely for what she ‘was about to tell me’ but said she needed to get it off her chest. Oblivious to the ‘bomb’ heading my way I was more than open to hear her comments. She proceeded to give me a 5 minute Coles version of what autism was while explaining that my son displayed all its related symptoms. Preoccupied with pregnant exhaustion and anxious to quiet my son from his then-happening tantrum, I warmly thanked her for helping me out, sorted out her pay, and apologized for any inconvenience my son may have caused her. Bewildered, I made my way home distinctly remembering justifying her every comment with good reason: “he would not look at me” (he is a shy boy), “he had no interest in the other children” (he has always enjoyed quiet play), “he played with one car for 2 hours” (he loves his red car), “he flapped his hands when the kids were excited” (he was just as excited as they were), “he did not speak to her” (he has always been a quiet boy), etc. etc. I didn’t do anything that night but reflect on her comments and allow them to smolder all night long. I know now that subconsciously I was mentally preparing myself for something ominous that lay ahead for me, my son and our family.

In the morning (after another terrible sleep of night-waking with my son) I opened my computer. Googled Autism and had an intimate 4 hour on-line dialogue which left me in tears, physically weak and mentally exhausted. I cried for about an hour until desperate sadness was replaced with determined panic. I spent the next 2-1/2 hours phoning any and every psychologist and pediatrician that I could find to provide me with some professional and personal advice. My desperation paid off and a qualified Psychologist agreed to meet with me, my husband and son to do a formal assessment of what we now know to be true. Five years ago my beautiful little boy was diagnosed with Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder.

Day #1 of autism continues to lie heavy in my heart, however we have lived with it and have learned big life lessons surrounding this neuro-developmental disorder. Looking forward I feel hopeful new parents entering this world will utilize and rely on the ever-expanding resources, links and professionals advocating on their behalf. If I had one wish, it would be for new parents, their family and friends touched by a similar diagnosis to embrace this life-long endeavour with love and hope. And trust that life will be good ~ just in a different way.

-Micheline

Grief, loss and joys in a family living with childhood disability

A question parents often ask is if they will ever adjust to the new and often unexpected reality of becoming a parent of a child with a disability. Emerging questions include: How will I cope? What will my child's life be like? How do I talk with my family about this? What impact will this have on my life? Even within couples, it is important to consider that both parents, as individuals, will ask these questions of themselves. Each person in a family has their own way of working through this, and understanding this reality. It is important to recognize that this is a natural process within families. Working through grief and loss eventually leads to some sense of acceptance. This process will be different for each family. Times when grief and loss can feel most profound are around a diagnosis and transitions.

Having a child with a disability within a family is an astoundingly interesting life experience. The gift of this child is that he/she is on a journey that follows twists and turns and ups and downs that no one could imagine. A child with a disability will change your life. You will experience highs and lows that no one can anticipate. You will wonder some days if you are going to make it through another day, and then when the next day comes, marvel that you got there! It is important to recognize that feelings of grief and loss are often infused or part of the experience of parenting a child with a disability. There are times when the experience of grief and loss is deeper than at other times. This is particularly true when there are changes in your child's particular condition, including behavioural challenges/changes; health concerns such as acute or chronic illness; changes in environments such as school; and when the needs of the child

with a disability make it difficult to adequately meet the needs of other family members.

Joy is a counter to the experience of grief and loss. Joy is that which permeates our world and sends a signal that everything is okay in this moment. It might be a smile, a sense of pride in seeing your child accomplish something, a picture someone gave you of your child, or something they told you about your child that you wouldn't have otherwise known. Perhaps something at school that was important was written in the communication book and you just beamed with pride and joy about that experience. It is not usually the big things that translate into joy but those day-to-day happenings that often occur instantaneously and make our world a bit brighter. A sense of joy evokes energy and counteracts the fatigue associated with grief and loss. Although both can occur at the same time, the moments of joy offer balance to the picture. That is what we hope for as family members of children with disabilities – a sense of balance in our lives.



Testimonial

The Journey Begins

A few days after Patrick was diagnosed with autism at three years old, I remember sitting on my couch feeling scared, sad, alone and uncertain about the future. As I stared out the window the phone rang. It was a mom from Patrick's baby group calling to chat.

As we were still digesting the news about Patrick ourselves, I hadn't told any of our friends about what we had just found out. My girlfriend talked about the weather, what she had been up to and at the end of the conversation she casually said "isn't it great now that our kids can say I love you? It sure makes the days when they have tantrums worth being a mom."

I sat speechless; you see Patrick was nonverbal so I had yet to hear him say anything. When I hung up the phone, all the emotions I felt burst out of me like a volcano. Tears swelled in my eyes and kept falling from my face. I couldn't stop crying.

A few minutes later, I heard little feet approaching. Patrick peered around the corner and saw me crying. He climbed onto the chair and sat in my lap. He kept staring at my face and at the tears that were rolling off my cheeks. He then began to wipe each tear with his finger. Every tear that fell, he caught them all one after the other.

After I had nothing left, he held my gaze. I remembering thinking how odd it was that he wasn't looking away as autistic children tend to not be able to hold eye contact. Then I realized, this was his way of saying I love you. At that moment, I knew that words were only one way to express your feelings. That's the day my journey with Patrick took a turn. I held his hand and promised him that I would never give up on him and that we would find a way down this path together.

– *Shino Nakane*

Grief and loss/adjustment to a diagnosis

How does one adjust to the experience of grief and a sense of loss that is directly related to becoming a parent of a child with a disability? This is an important question to consider. No one walks in your shoes, although many have travelled a similar path. It is important to acknowledge that parents often grieve for that sense of what their child may have done with their life had they not had a disability – the loss of the child they dreamed or hoped for. It is common to have these feelings and all or most parents will experience this.

However, it is also unfair to dwell on this concern as it can diminish the experience of what is an important life experience. Being a parent of a child with a disability is a life experience that has many challenges to overcome but also many unexpected joys to anticipate. Yes, it is possible to regain balance and get on with life.

Testimonial

My son was four years old when I took him to see a doctor of alternative medicine. I was searching for anything that would help my child to be healthy and well. Still hopeful that he would possibly walk and communicate, I was ready to go to the ends of the earth and listen to anyone who might be able to offer treatment or a “cure” for him.

Following a lengthy examination, the doctor smiled and said, “Your son is remarkable. He is an old, old soul and his job is to watch, to listen and to teach us. He will never need to worry about the complexities of MasterCard.”

Something inside my brain clicked. Of course he was perfect! The only shift that was needed was for me to stop comparing him to anyone else.

When we got home, I took out my calligraphy supplies and penned a new mantra for my new way of thinking. It read: “I am myself; it is everything I need to be.” I hung it on the wall in my son’s room and still look at it every day.

– *Brenda*



Unit 2

The Family

Nurturing your partner/marital relationship

Nurturing your relationships with your spouse or partner is very important. Parents of children with disabilities are the primary support for each other. Family life today is stressful. People are busy and have multiple commitments demanding their time. In some families, the needs of the child with a

disability are a major focus. Although meeting the needs of the child is important, attention to the couple relationship is also critical. Part of the work of any relationship is to find ways to spend time together, apart from other commitments and responsibilities.

Spending time with your spouse or partner is an important component of self-care. How do you build this in?

- Take time at least once a week to spend time alone as a couple. Negotiate this time with each other and make arrangements so this can happen.
- Schedule a weekend away a few times a year. This is important for all couples.
- Find respite, child care resources, or extended family members and friends who can help you as a couple to have some time alone.

- Engage in daily communication with your spouse/partner related to family issues and other aspects of your lives.
- Keep the lines of communication open. This reduces misunderstandings and assumptions.
- Share the responsibilities. For each couple this will be different. The best way to share the responsibilities needs to be negotiated and realistic for each couple.
- Relationships in couples need to be refreshed and renewed.
- Think creatively about ways in which to nurture and care for each other as this will enhance your life as a family.

Siblings

Paying attention to sibling relationships is important. There are unexpected joys and also unexpected challenges.

I can't imagine my life without Kate as my sister. I became a teacher because I wanted to work with children with disabilities. I always got to help my sister and teach her things, and along the way, she taught me a thing or two!

It was tough! I always felt like Mom was so focused on Luke that I didn't get much attention. I was jealous sometimes of all the time it took for her to do everything for Luke and I didn't think she even noticed that I might need something. I had to figure out a lot of things for myself. I just wished that she could have spent as much time with me. Don't get me wrong, I love my brother and would do anything for him, I just wanted to have more of my Mom's time.

The lives of children with disabilities are influenced and shaped by other members of the families such as brothers and sisters. While recognizing that the needs of your child with a disability may be higher than their siblings, it is critical to be aware of the needs of all children within the family. How do you do that? It is particularly challenging at times and responses will differ, depending if you are in a single- or two-parent family. Parents each have their roles within a family, so it is important to

have ongoing communication between parents about how all the children are doing. Part of the challenge is that the needs of your child with a disability are highly visible. Whether that includes physical needs, behavioural needs or constant supervision, you know what has to be done to help your child to be safe and secure.

Siblings need time with their parents and often adjust very well to being a brother or a sister of a child with a disability. It is important to think about how you can pay attention to the needs of siblings while attending to the needs of your child with additional needs. How do you do this?

- Think about each child as separate and unique.
- Think about who they are as individuals and their differing needs.
- Think about how you can attend to a sibling even though you have an intense focus on your child with a disability.
- Take time to observe your children and how they engage with each other, and with you.
- Remember that children don't always express their needs and concerns openly, especially if they see you worried.

It is important to be aware of individual as well as family needs. Identify a way that you can spend time with each of your children. If the sibling displays frustration or jealousy of the attention you pay to the child with a disability, this needs to be dealt with by open communication. Allow siblings to express their thoughts and feelings. It is natural for siblings to have some rivalry and this occurs in all families.



Each child develops at a different pace. Being aware of the developmental needs of your child with a disability is helpful. Siblings can be a great benefit to a child with a disability. They often do not perceive the differences of their brother or sister the way a parent might. There is less inhibition on the part of siblings to simply engage with each other in play, affection, meals and routines within the family. A sibling is an important resource within a family and interactions such as play just come naturally. Playing together is a benefit to all siblings, while this important activity also offers stimulation to the child with a disability. Social interaction and play are a critical part of early child development and family life is the most important place this occurs for a child with a disability. The love a family member has for a child with a disability may be one of the most important highlights in going through life.

Testimonial

It was a beautiful summer day as I sat on our front porch watching my two oldest sons (aged 4 and 5) racing their tricycles up and down the sidewalk in front of our house. Holding my three year old, my eyes welled up as I wondered if he would ever experience the feeling of the wind in his face and the adrenaline rush of a bike race with his brothers. A profound sense of sadness washed over me as I listened to his brothers laughing and screaming as they played. I felt overwhelming grief for all the things that he would not experience and the milestones that we would not celebrate. It was a devastating moment.

A few days later, my son's physical therapist came for a home visit. When I opened the door, she had parked an adapted tricycle at the bottom of the steps and her first words to me were, "I have something to try!" The bike had a back support and wide seat complete with seatbelt and strapping, foot blocks and straps on the pedals and wrist straps on the handlebars to keep his hands in place.

Within 30 minutes, my son was out on the sidewalk with his brothers with the wind in his face and laughing as he crossed the finish line! On that day, my tears were joyful.

– *Brenda*

Birth order and your family

Birth order is an important consideration in relation to issues of grief and loss as it often shapes the way that family members adapt to a member with a disability. If your first child is born with a disability, as a new parent you often don't know anything different other than learning how to respond to the situation at hand. You just keep going one day at a time and meeting each challenge. However, when family constellations change, it is

important to recognize there will be an impact and you will need to find ways to manage new demands. Having a second child (or more) who does not have a disability influences your perspective on the needs of the child who has the disability. Raising a second child who does not have high developmental needs is a new experience. The challenge remains finding balance, support and ways to cope.

First-born children with disabilities

A first-born child who is not diagnosed with a disability at birth presents unique challenges. Parents do not have the experience of a previous child who has met developmental milestones more or less on time. As parents, many of us read about child development, as so many resources are available today through the Internet, library, and community-based

resources such as community health. When a child receives immunizations, information is often exchanged between the parents and the community health nurse about child development. New parents do not have to know everything and are not always aware of potential indicators that there is a problem.

Extended family

Extended family connections and supportive relationships are important for families who have a child with a disability. Extended family is usually defined as relatives such as grandparents, aunts, uncles and cousins. Sometimes extended family members live close by and are available to offer support. The ways in which families can be supportive include: visits at home, family outings, attending medical appointments with you, providing child care occasionally if possible, and being available as a contact in an emergency. Support looks different for each family.

It is important to talk with extended family members about the ways that they can offer support to you and your child. Why is this important? Many family members do not know the best way that they can offer support. Some family members are in a position to offer help while others may have difficulty coping with the situation or may not have time to help out. Some will ask the question: How can we help? Others won't. There are many reasons

for this including fear of what the disability means, worry about medical conditions and not knowing what to do. This is surprisingly common within families.

Meeting with family members and having conversations about how they can best support you is helpful. Call a family meeting. Ask a professional if they are available to talk with family members or possibly even attend the meeting. Extended family members often have many questions and don't know how to ask them. Remember, they are also going through their own process of grief, loss and worry. Grandparents worry not only about their adult children who become parents of a child with a disability, but their grandchild too. Each family member will cope with this situation in different ways. Some family members will be able to help and some won't. If a family member is willing and able to help, find a way to make this happen. If you become aware that a family member is unable to help, find a way to accept this situation.

How do you develop supports when your family lives at a distance?

For families who are not in the same area, it is important to consider ways to develop supportive relationships. When families and relatives are not close by, it is important to create and establish relationships with friends that become like informal family connections. While not related, a bond can exist with friends that can be very supportive and helpful. This connection can be very important for immigrant families, where relatives are

in another country. Establishing connections within cultural groups can be a way to create a support network within the community. There are national and international phone plans through different companies today that can also act as a means to bridge the gap between families today. Families also have ways to connect via the Internet and this is another means of maintaining regular communication.

The foster family

Foster families often become caregivers of children with disabilities who are placed in the care of Children and Youth Services. Reasons for children with disabilities being placed in foster families include:

- Children who are surrendered at birth up to the age of 18 (in Alberta), possibly for adoption.
- Children who are in need of protection and temporarily or permanently placed in care.
- Children who require specialized care that the family is not able to provide and are placed in care by agreement with the family and child welfare authority.

In a 2005 study by Sobsey and Calder, several key areas were identified as needs related to support for families who have a child with a developmental disability. Support related to counseling, respite assistance, developmental issues, school, better administration of services and better quality follow-up were key needs for families. Professionals working with foster parents, particularly when there are multiple placements of children with

disabilities, should be sensitive to needs that support placement stability over the long term. It is also important to recognize how changes within the home, such as additional placements, can impact children with disabilities. It is important that foster parents have access to resources that will help them effectively attend to the needs of children placed in their home and their own family members too.

The adoptive family

The process that leads to adoption can be complex and it is important to understand the ways in which a child becomes adoptable. Children are surrendered for adoption (in Canada) through three routes. The first route is through a private adoption agency. Private agencies work closely with potential adoptive families and birth mothers/fathers/families in order to create an adoption plan. This planning is generally done by a social worker and an agreement is made about the exchange of information between birth and adoptive fami-

lies. In some situations, both families agree to ongoing contact that can range from an annual update to visits. Plans are negotiated on an individual basis that is agreeable to birth and adoptive families.

The second route to adoption is through a child welfare agency. The majority of child welfare work in Canada is a provincial or territorial government responsibility, through a Children's Aid Society or delegated First Nations Agency in different communities across the country. Children become eligible

for adoption either after they are relinquished, or apprehended and made permanent wards of the government. A general framework guiding adoption practice is permanency planning. Prior to adoption, children who have disabilities are often provided care through foster families or agencies that meet the requirements to care for children with developmental disabilities. An adoptive placement is made as soon as possible, once all legal requirements are satisfied. In the case of child protection concerns, children are often adopted by grandparents, or extended family members [in agreement with child protection authorities] who make a lifelong commitment to care



through adoption. In situations where a child has severe disabilities, or medical conditions requiring specialized care, post-adoption agreements are made with child protection agencies.

The third route to adoption is through international adoption agencies. Those considering international adoption need to research Canadian agencies involved in this work and make careful decisions about the responsibility of adopting a child with a disability from another country. Another consideration is the financial costs associated with international adoption. This is a process that requires support from a professional agency and dialogue with all family members, within the family and extended family.

Parents who adopt children with disabilities are usually provided as much information as possible about the child's disability prior to placement. Sometimes this information is not available or not disclosed to the adoption agency. Although rare, some families can adopt a child with a disability that is not evident or diagnosed prior to the placement. Once an adoption is finalized through the courts, parents have full legal rights and responsibilities to care for the child.

Many adoptive families knowingly adopt a child with a disability because they want to have a family. Other families feel they have room in their hearts and homes to make this choice. Sometimes foster families adopt children with disabilities placed in their home simply out of love and a strong bond that leads to a choice of adoption. There are many reasons why parents may choose to adopt a child with a disability with knowledge about what this means for the child and for their family.

Dear Liz

When you were born [we] were living in Calgary, entirely unaware that you existed. I think often of all the circumstances that conspired to bring you into our orbit, thirteen months later, all the decisions and chance events and impulses that separately seem accidental, but which together bear the mark of some benign cosmic mischief... You got off to a rough start Liz. You were thirteen weeks premature and weighed only two and half pounds at birth... You lived in brightly lit hospital rooms, your sleep interrupted by needles and pain and the noise of the machine at your bedside that did your breathing for you. No wonder you don't like loud noises, and have what they call Attention Deficit... Now, here you are at age seven... part of a family and already in your young life a vital part of the community and a rich and welcome presence in other lives... We want you to appreciate the remarkable way people are drawn to your subtle spirit; we want you to realize the special intelligence you possess that discerns feelings as well as ideas; we want you to be proud of the toughness and thirst for life that has seen you through so much illness. You have already learned to compare yourself to others – one of humankind's favorite ways of feeling miserable. We hope that you will also come to realize that in all ways that really matter, you are irreplaceable, and beyond compare.

Love from Dad

Source: Jordan, J. Letter to Liz. In: Badry, D., McDonald, J. R. & LeBlond, J. (eds.) (1993). Letters to Our Children. Calgary, AB: Faculty of Social Work, University of Calgary and Alberta Children's Hospital. (21-22)

Many adoptive parents believe that adopting a child with a disability will enrich their lives, the lives of siblings and the community. These adoptions are born from a profound belief in the worth and dignity of each person, and out of love.



Unit 3

Special Considerations

Working parents

It is important for parents to think about child care when they have a family. This task is stressful and families need to become aware of the different choices they have. If you have to arrange child-care because you are returning to work, a day care or family day home are both options. It is important to check if your child care options have supports in place to effectively manage your child's needs. Some parents may have extended family such as grandparents or other relatives who are willing and able to provide day care, but that is not always a viable option. Parents can work with professionals such as community health clinics or social workers in counseling agencies to find information about the options available to them. It is important to consider how the option you choose will meet your child's needs

and to get as much information as possible about the agency's experience with children with disabilities and the supports that may be available.

Returning to work can take an emotional toll on any new parent. This is particularly difficult with children who are medically fragile or have behavioural concerns. It is important to address all these issues through conversations with the potential care providers prior to making formal arrangements. Have meetings with the agency intake coordinator and take a list of all the questions you have. Day cares and family day homes are operated by agencies that are licensed and screen care providers. Private child care is another option. Some families have the financial resources to have a nanny live in or have a private caregiver

(babysitter) care for their child at home, while they are at work. Other parents arrange private child care and take their child to a caregiver while they are at work. There are benefits and risks associated with all these choices and families need to determine what is best for them. However, this process should begin by carefully reviewing each option and gathering important information.

Child care may take place in a day care, day home or through a private caregiver/babysitter. Some children with disabilities have needs that make them eligible for services in early intervention programs. Early intervention day programs for preschool children may be part time or full time. Early intervention programs may be full day or you may need to find child care for the remainder of the day. Sometimes, programs work together to provide full-day service, but this may not always be the case and you may have to make alternate arrangements that work for the family schedule.

It takes time to adjust to whatever choice you make for alternate care or when

your child begins a new program. Open communication, regular contact and ensuring regular payment of fees for child care are all very important parts of the relationship you have with your child care provider. If you have concerns or problems in a licensed day care or family day home, you can contact the agency or licensing body to address these concerns. If you have made private arrangements and there are concerns, it will be your responsibility to directly address them with the caregiver. Licensed child care or monitored family day homes are in some ways preferable because of the monitoring that is available and the potential for support to the provider. Having someone else care for your child is always challenging, but it can also be of great benefit to your family. If you have to work or choose to, you need child care. Your child can benefit from the care provided by others as well contact with other children in the day care or family day home.

Single parents

The single parent of a child with a disability, and the single mother in particular, has become relatively common today. Both single mothers and single fathers are raising children with disabilities. The demands of caring for a child with a disability can affect relationships between spouses and partners and strain the relationship to the point of a breakdown.

The life of a single parent of a child with a disability is not easy. The biggest challenge is finding time to respond to multiple demands. A critical factor in being able to respond to demands is building a strong support

system. The support system for single parents includes child care for working parents and for taking respite; extended family involvement if possible; maintaining friendships and social connections; and professional supports such as counseling if required. As a single parent you can easily become isolated without a support system in place.

When the needs of a child are too great for one parent, (which is generally true for most children with or without a disability), it is important to deeply consider and discuss with a trusted friend or professional a way

to get the support you need. Single parents of children with disabilities face many challenges. The needs of the child may not allow the parent to work, thus poverty becomes a problem.

Another challenge of single parenting is isolation. Even two-parent families have this experience in raising children if one spouse is frequently away from home for work. However, in two-parent families, breaks are often built-in because someone else is around if you have to run to the store to get something, or

even just want to go out for a walk on your own. Everyone has the need for time alone occasionally. Therefore, a structure needs to be established in the single-parent home that will help to meet the needs of both the child/youth and parent for respite. Many single parents find ways to build supports and learn to adjust and cope with the needs of their child. It is important to work with professionals who can help you determine what works best for your family.



Unit 4

Family Wellness

Developing natural supports

Natural supports are those we find within our families and communities. The family is the basic structure within society. For some people, friends may be their only family and they work hard at creating relationships that will nurture and sustain them. These relationships are generally established through involvement in the community, whether that is in the neighbourhood, in the work force, in volunteer work, through different clubs, organized sports, faith communities, schools and other places where people gather. People are social and need others to live fully. People who become isolated often do not have a lot of natural supports.

There are many challenges in maintaining natural supports. Even though one may assume that natural supports such as family should always be there for each other, this is not always the case. Natural supports are living systems that are dynamic and subject to change. If you do not have a support system, you must reach out and start to develop a network that can be part of your life. Raising a child with a disability requires many people, and establishing a nurturing and caring network of supports can sustain families as their child grows from childhood to adulthood. For others, immediate family is their primary source of support.

Self-care

One of the most important things you can do as a parent of a child with a disability is take good care of yourself. This is important and it is not selfish. As parents, our children depend on us to meet their every need. When you are parenting a child with a disability, it is critical to reflect upon just how much you can give. The need will always be there to care for your child. The question becomes: How do you find the energy to meet the need for care over the long term? It is important for families

to talk about how spouses, partners, extended family and friends can be helpful. When you think about the help you need, be practical and realistic. High levels of stress are associated with caring for a child with a disability and you need to find ways to cope. Self-care could also be called stress management. When a parent is stressed, it has a ripple effect on the rest of the family.

Basics about self-care when you are a parent of a child with a disability

Establish a support system. If you take care of yourself, it is easier to care for others. Identify who your supports are and make sure to connect with them as needed. Your support system can include family, friends, neighbours and professionals.

Know what resources exist in your community. Is there a library that you can go to for activities and events? What recreation facilities exist? Involvement in your community reduces feelings of isolation.

Recognize that you will have ups and downs. All families do. There are time of increased demand occasionally, but recognize it won't last forever. Don't be too hard on yourself during the down times. Write things down in a journal so you have an outlet for your feelings. If you can't talk with your partner or spouse, identify someone you can call in a crisis, whether it's a friend, family member or even a crisis line. Use your supports.

Respite. Respite is a break from the demands or caring for your child and is a critical part of self and family care. Use respite purposefully and think in practical terms about what would revitalize you and your family. Create a budget for your time. Plan your breaks and build them into your weekly, monthly and yearly schedule. Getting out for walks, going out for coffee with a friend, going to a movie and/or dinner, playing a game, reading a book, and building in a vacation are important in practicing self-care. Think about who can provide respite and know that many family support and disability serving agencies offer some form of respite.

Self-care is probably one of the most difficult concepts for any parent to master. Parents seem ever available to meet the needs of their children. The dependency of children upon their parents is a given. Children always need their parents to look after them, particularly when they are young and vulnerable. For children with disabilities, these needs may increase and be lifelong. How does a parent nurture and care for him or herself throughout this process? The best way to care for a child with a disability over time is to find opportunities for growth, development and nurturing as an adult who has needs. Finding balance is an essential challenge for parents.

Strategies for self-care

- 1) Find one evening a week where you can do something for yourself. Sometimes finding more time than this is not possible. Enlist the support of others in order to find some time and space for yourself. This could be family members, partners, or alternate caregivers that provide respite. You can determine what works best for you in terms of how you want to spend the time. Although it may seem challenging to set aside a few hours a week for yourself, you will discover that this is important in maintaining energy and balance in your life. Remember that many family support and disability serving agencies offer some form of respite.” This would go after “This could be family members, partners, or alternate caregivers that provide respite.”
- 2) Recreation/Exercise – What do you like to do for recreation? Engaging in exercise is known to help maintain health and energy. Both of these are important to your overall sense of personal wellbeing as an individual person and as a member of a family. Taking care of yourself is not selfish. It is important for mental and physical health. When you take care of yourself, it is much easier to care for others in your family.
- 3) Identify resources that will help you to engage in self-care. Take time to reflect on what you need to find balance in your life. Talk to friends and families about your vision for self-care. We all have lives apart from our children. Make a plan, write it down and commit to this plan. As much as children with disabilities need a circle of support, so do their parents.
- 4) Use respite – Many disability serving agencies offer some form of family support or respite services. This can be an important resource for families. Respite and child care are not the same thing. The purpose of respite is to give you a break. This is different than your regular child care arrangements for when you are at work. Respite may be offered in your own home or outside your home. Think in practical terms. What do you need and who can offer support to you? Write a list. What would be most helpful to you?

Some examples:

Is there someone in the family or a neighbour who can cook a meal once a week so you have one less thing to do? Is there someone who can watch your child so you can get the grocery shopping done? Is there someone in the family or your support network that can do the shopping if that works for you? Identify who can support you with respite and make concrete plans about what this will look like for your family.

Strategies for seeking help might include:

- Be clear (concrete) about what kinds of things you would find helpful.
- Involve others in planning and problem solving
- Trust in the abilities of others to handle your child or say no.
- Identifying what others would need to feel comfortable providing care for a child with disabilities.

Time

Let's talk a little about time. Often a focus on the child with a disability is required and this is necessary at times due to physical care, medical care and supervision needs. Children are already dependent upon their family to meet their needs when they are young. It is important to recognize that it takes a lot of time to care for a child who has a disability. Trying to balance the needs of the child with a disability in relation to the needs of other family members, including brothers and sisters, partner or spouse, is a challenge.



It seems there is always a demand on your time and often there is no time to just stop, think and be. Before you know it, you are caught in an increasing cycle of demands from within and outside the family and wondering how you got to this point. One of the tools that can support managing these issues is a time management strategy within your family. Many families of children with disabilities become highly organized with their time as there are bus schedules, school schedules, and health-related appointments that all need to be considered. It also is time consuming to schedule supportive resources such as those required for respite, transportation, child care and other needs. Each family has their own unique needs to consider, and this has to be factored into the equation of just how much time everything takes, and how to manage that time effectively. Organization with the use of calendars and a time management plan will help reduce your stress as a family member, diminish that sense of always feeling 'on the go' and perhaps help you find a little time for yourself.

Unit 5

Encouraging Social Skill Development and Friendships

Where do children with disabilities develop relationships with others?

- In their families – immediate and extended
- In the community – neighbourhoods, recreational facilities and church
- In preschool, day care and school over 12 years or more
- In relation to adults such as medical professionals and caregivers

Why is this important?

- Everyone needs friends.
- Friends care for each other.
- Friends teach each other how to be in relationship.
- Friends grow in their relationships over time.

Social skills develop in relationships with others. Children with disabilities need their families, friends and community to develop social skills. What are the ways this can happen? Get your child involved in activities where they will spend time with other children. It is important to establish a social net-

work early on in your child's life. Connecting with others outside the family is a natural part of development and an experience that can enrich your child's life. Connecting with others in the community promotes interactions that are key to social skill development. What does your child offer others? Through presence in

the community, children with disabilities teach others about living a life with a difference. This is a gift your child can give others. It is often surprising what kinds of connections are made. These connections are important early in life as they begin to establish a network that is important for a child with a disability over their lifespan. Children with disabilities will continue to grow and develop as their peers do and creating friendships are important. Helping your child to connect with others and be a part of events such as outings and birthday parties are valued life experiences for all children.

Community recreation is one venue for inclusion. Some cities and towns may have organizations that promote community engagement for children with disabilities and their families. One example of this is the Rotary Club, an international organization that has worked with communities in relation to adaptations and accessibility in community recreation facilities. The Calgary Rotary Challenger Park (<http://www.challengerpark.com/>) has developed a space in Northeast Calgary where all children can play. Often, accommodations made for people with disabilities benefits everyone. Ramps are a good example of this and often preferable to stairs for many people. Another example of a recreation club for children with disabilities in Calgary is Between Friends (<http://www.betweenfriends.ab.ca/>).

This organization brings together children and adolescents with disabilities and volunteer peer mentors to spend time developing friendships and engaging in recreational activities. Their core values are drawn from the word FRIENDS and include: fun, respect, inclusion, equality, no barriers, diversity and skills. These core values are representative of the importance of social relationships. Having friends and relationships outside the family is important for children and adolescents and supports the development of social skills from childhood to adulthood.

The key to inclusion is finding activities that children enjoy and working/negotiating with the facility to identify barriers and required accommodations. Inclusion is a value that families have and it is important to engage in communication that will open doors to opportunities for their child. Many organizations have volunteers who are available to work with and offer support to children with disabilities. It is important for parents to explore the types of activities that will facilitate developing friendships through involvement and presence in the community. Parents always want to protect their children from experiencing hurt or even discrimination because of their disability. The reality is that living life with a difference means, somewhere along the way, experiences of rejection and exclusion are bound to happen. This is a part of life for all children. However, it is important to protect children with disabilities due to their particular vulnerabilities. It is also important to ensure adequate safety measures are taken, such as a child carrying identification and contact information for family. Children with disabilities have as much right as everyone else to enjoy the freedoms of life and parents have a major role in developing connections that will support inclusion.



References and Resources:

Website Links

Family Supports for Children with Disabilities

<http://www.edmontonandareacfsa.gov.ab.ca/publish/414.cfm>

Raising children network of Australia

http://raisingchildren.net.au/articles/raising_a_child_with_a_disability.html

Raising children network of Australia – single parents of a child with a disability

http://raisingchildren.net.au/articles/parenting_alone.html/context/1000

Bloom - Parenting children with disabilities (Toronto blog by a mother)

<http://www.blogger.com/profile/05901482901008134549>

Autism Inspiration

<http://www.autisminspiration.com/?gclid=CNvSz7Gz9aYCFR4hgwodDGXfbA>

Calgary Rotary Challenger Park

<http://www.challengerpark.com/>

An Article by Alan Shain about Parents of Children with Disabilities

<http://www.hemikids.org/inspiration/shain.pdf>

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Also visit our web site to see the Parents Roundtable Video

References and Resources

Here are some references you might find helpful:

Module 2:

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- Cross-Cultural Lessons: Early childhood Developmental Screening and Approaches to Research and Practice Handbook* via: <http://www.cup.ualberta.ca/culturalvalidity>
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Module 5:

Adapted from parent fact sheets on the Bully Free Alberta website at <http://www.bullyfreealberta.ca/>

Building on Success: Helping students make transitions from year to year <http://education.alberta.ca/media/352661/build.pdf>

Children and Youth in Transition: An Alberta Children and Youth Initiative
http://www.child.gov.ab.ca/home/documents/youthprograms/Guidelines_for_Supporting_Successful_Transitions_for_Children_and_Youth.pdf

FASD Support Site – Fetal Alcohol Spectrum Disorders – Bright Tomorrows http://fasd.brighttomorrow.com/index.asp?page=3_1_1

A Handbook for Parents of Children Who Are Gifted and Talented, 2004 <http://education.alberta.ca/admin/special/resources/journey.aspx>

The Journey – A Handbook for Parents of Children Who Are Gifted and Talented, 2004 <http://education.alberta.ca/admin/special/resources/journey.aspx>

The Learning Team – A Handbook for Parents of Children with Special Needs, 2003 <http://education.alberta.ca/admin/special/resources/learningteam.aspx>

Our Words, Our Ways: Teaching First Nations, Métis and Inuit Learners <http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

Re: Defining Success - A Team Approach to Supporting Students with FASD (2009) <http://education.alberta.ca/admin/special/resources/re-defining.aspx>

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope (2004) <http://education.alberta.ca/admin/special/resources/fasd.aspx>

Module 6:

The Learning Team – A Handbook for Parents of Children with Special Needs, 2003
<http://education.alberta.ca/admin/special/resources/learningteam.aspx>

Our Words, Our Ways: Teaching First Nations, Métis and Inuit Learners <http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

Module 7:

Jordan, J. Letter to Liz. In: Badry, D., McDonald, J. R. & LeBlond, J. (eds.) (1993). Letters to Our Children. Calgary, AB: Faculty of Social Work, University of Calgary and Alberta Children's Hospital. (21-22)

Sobsey, D. & Calder, P. (2005). State of the Evidence Review – Family Supports for Children with Disabilities. Retrieved online February 28, 2011 from <http://www.research4children.com/admin/contentx/default.cfm?PageId=921>

Website Links:

Here are some website links you might find helpful:

pbsc.info/family/

Module 4:

http://dese.mo.gov/divspeced/FirstSteps/pdfs/earlyinttmmdl%20_01_06.pdf

www.fippcase.org

<http://specialquest.wikispaces.com>

Module 5:

<http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

<http://education.alberta.ca/admin/special/resources/re-defining.aspx>

<http://education.alberta.ca/admin/special/resources/learningteam.aspx>

<http://education.alberta.ca/admin/special/resources/journey.aspx>

<http://www.bullyfreealberta.ca/>

<http://education.alberta.ca/admin/special/resources/re-defining.aspx>

http://fasd.brighttomorrow.com/index.asp?page=3_1_1

<http://education.alberta.ca/media/932765/redefining-action6.pdf>

<http://education.alberta.ca/admin/special/resources/fasd.aspx>

<http://education.alberta.ca/admin/special/resources/learningteam.asp>

<http://education.alberta.ca/admin/special/resources/fasd.aspx>

<http://education.alberta.ca/media/352661/build.pdf>

<http://education.alberta.ca/admin/special/resources/re-defining.aspx>

http://www.child.gov.ab.ca/home/documents/youthprograms/Guidelines_for_Supporting_Successful_Transitions_for_Children_and_Youth.pdf

<http://education.alberta.ca/admin/special/resources/fasd.aspx>

<http://education.alberta.ca/admin/special/resources/journey.aspx>

Module 6:

Canadian Websites Related to Medical Transitions

The Family & Community Resource Centre

<http://fcrc.albertahealthservices.ca/>

Alberta Children and Youth Initiative

<http://www.seniors.alberta.ca/disabilitysupports/documents/TransitionPlanningProtocol.pdf>

Children's Link Transition Manual

http://www.childrenslink.ca/pdf/templates/transition_manual.pdf

BC Children's Hospital

<http://www.aboutkidshealth.ca/BCCH/EN/ResourceCentres/Pages/default.aspx>

Canuck Place - Vancouver

http://www.canuckplace.org/family_kids_corner/resources_support/financial_and_medical_benefits.php

Children with Intellectual Disability – BC ACL

<http://www.cw.bc.ca/library/pdf/pamphlets/SH16.pdf>

Transitions for Youth with Disabilities – BC

http://www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf

<http://www.cw.bc.ca/library/pdf/pamphlets/PositioningMobilityTransition2009Read.pdf>

CanChild Centre for Childhood Disability Research – McMaster University

<http://www.canchild.ca/en/ourresearch/priorities.asp>

Youth Transition – YouTube plus other resources

http://www.canchild.ca/en/canchildresources/youth_kit.asp

Articles link

http://www.canchild.ca/en/ourresearch/articles.asp?_mid_=2458

Persons with Disabilities Online

<http://www.pwd-online.gc.ca/pwdh.4m.2@.jsp?lang=eng>

Health Care Transitions

http://hctransitions.ichp.ufl.edu/products_planning_guides.php

http://hctransitions.ichp.ufl.edu/pdfs/HCT_Workbook_18up.pdf

Transitions to Adulthood for Youth and Children with Disabilities (2008) Canadian

<http://cirrie.buffalo.edu/encyclopedia/en/article/110/>

Transitions to Adulthood – University of Alberta

<http://www.rehabmed.ualberta.ca/transitions/>

American Websites

Ability Online Community for Youth with Disabilities

<http://www.ablelink.org/public/new/index.html>

<http://www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know>

Cincinnati Children’s – all the links below are part of this site.

<http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/transitions.htm>

<http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/get-started.htm>

Parent Handbook

<http://www.cincinnatichildrens.org/assets/0/78/1067/1395/1957/1959/578174fc-6872-4b7a-9a64-03a6ff6f88d5.pdf>

All About Me Form

<http://www.cincinnatichildrens.org/assets/0/78/1067/1395/1957/b2ea7ed3-d099-4fe0-8597-590b9e58f690.pdf>

I am the child poem

<http://www.oafccd.com/lanark/poems/child1.htm>

New Journal Article

Parenting Children With Disabilities: Navigating Through the Storms Journal of Creativity in Mental Health

Volume 5, Issue 1, 2010, Pages 87 - 92

Author: Margaret Costantino [show biography]

DOI: 10.1080/15401381003627335

<http://education.alberta.ca/teachers/resources/cross/ourwordsourways.aspx>

<http://education.alberta.ca/admin/special/resources/learningteam.aspx>

Module 7:

Family Supports for Children with Disabilities

<http://www.edmontonandareacfsa.gov.ab.ca/publish/414.cfm>

Raising children network of Australia

http://raisingchildren.net.au/articles/raising_a_child_with_a_disability.html

Raising children network of Australia – single parents of a child with a disability

http://raisingchildren.net.au/articles/parenting_alone.html/context/1000

Bloom - Parenting children with disabilities (Toronto blog by a mother)

<http://www.blogger.com/profile/05901482901008134549>

Autism Inspiration

<http://www.autisminspiration.com/?gclid=CNvSz7Gz9aYCFR4hgwodDGXfbA>

Calgary Rotary Challenger Park

<http://www.challengerpark.com/>

An Article by Alan Shain about Parents of Children with Disabilities

<http://www.hemikids.org/inspiration/shain.pdf>

Your Turn - Answer Key

Module 2: Unit 1, Topic 1

Yes! Remember, something qualifies as a positive reinforcement if it increases the occurrence of the behaviour that it follows. Even though this may not be reinforcing for you or for other children, if it is for your particular child, then it is something that you may wish to use. This is important to remember as you may have to search to find something that is reinforcing for your child. Reinforcement can be highly individualized.

Module 2: Unit 2, Topic 3

Example	Antecedent(s)	Behaviour(s)	Consequence(s)	Likely to occur again?
Example 1	-Setting up for the activity—getting out book, TV off -Telling her it is reading time -Parents asking her to point at pictures in the book	-Pointing at pictures	-Clapping -Ice cream	yes
Example 2	-Getting out socks -Prompting him to stretch his socks	-Screaming -Hitting -Biting	-Stop prompting him -Do it for him	yes
Example 3	-Getting ready for snack -Mom telling him to use his spoon	-Feeding himself with a spoon (motor activity)	-Gets to eat his favorite food (yogurt)	yes

Module 2: Unit 4, Topic 2

- Teaching him an appropriate way to say “no” when asked to play with his sibling
- Teaching him to request a break when he becomes bored or frustrated with the activity
- Increasing his play skills to decrease frustration

Module 2: Unit 5, Topic 2

Monday = full physical prompt

Tuesday = partial physical prompt

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- Brenda McInnis
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- Krista Miller
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Made possible with the support of the Government of Alberta.

Positive Behaviour Supports for Children

Reaching for the Stars

An E-Learning Website for Families of Children with Disabilities

If you have a child with disabilities you will have experienced both joy and challenges.

Positive Behaviour Supports for Children is designed to enhance your capacity to promote adaptive behaviours and developmental skills, while managing the challenges you face.

This engaging and user-friendly website includes video and interactivities to help you experience the joys of parenting a child with a disability.

www.pbsc.info/family/

