

Prepare to Launch

A Resource Guide for Parents of Adolescents with
Autism Spectrum Disorder

V3.0

*launch*TM 
fuelled by knowledge

Letter To Parents

You want the transition between the teenage years and young adulthood to go as well as possible for your child. This Guide offers useful information on how best to manage this transition.

The Launch program has organized the key content into five domains. Information and practical advice about each domain is included in the Guide along with a Transition Planning Timeline that highlights important tasks for various ages and stages of development. The Guide also contains resources and programs for each domain area, references to other guides, online reports and books. To further augment these written materials we have created an interactive online planning tool and a short video that reviews key topics within each domain. Both are available to you on The Ability Hub website (www.theabilityhub.org).

We hope this Guide provides you with a positive outlook on this critical phase of parenting. Perhaps the guidance and resources included in it will help make parenting an adolescent or young adult with ASD a little easier.

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Acknowledgements

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Reference

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Available at: www.theabilityhub.org

About The Ability Hub

The Ability Hub is an initiative of The Sinneave Family Foundation. (Sinneave or the Foundation).

The Ability Hub is a 17,000 square foot space located on the 3rd floor of the University of Calgary's Child Development Centre, in Calgary, Alberta. As one of the first initiatives of Sinneave, the Ability Hub is a centre of information and a welcoming space to facilitate the advancement of promising practices and innovative pilot programs and models geared toward increasing the independence of the growing population of adolescents, adults and families living with Autism Spectrum Disorder. Launch is a key Foundation-led initiative at The Ability Hub.

The Ability Hub was designed to address the needs of those with ASD-related sensitivities and includes architectural features that minimize distractions, such as sound-dampening panelling and floor tiles, quiet lighting, curved walls, and colour-coded signage to help individuals transition successfully. The space serves as a model for service providers, schools and even families who are looking for best practices in creating positive, welcoming and practical environments for individuals living with ASD. The facility is divided into classrooms, therapy rooms, multi-purpose rooms and a self-contained apartment which are all utilized by the various initiatives to enable their development.

One of the ways the Foundation collaborates with the community is to open our doors to autism-related demonstration programs, workshops, presentations, tours and meetings. If your organization wishes to learn more about accessing The Ability Hub venue, please contact us.

For general information, or to arrange a tour of The Ability Hub, please call: (403) 210-5000 (toll-free: 1-888-733-7976), or e-mail: ambassador@theabilityhub.org

The Launch Program

Transitioning from adolescence to adulthood can be a trying time for youth - particularly for those with ASD. Individuals on the autism spectrum face a number of challenges related to health and support services, housing options and community perceptions. These challenges can result in limited social, vocational and recreational opportunities. By supporting parents and other caregivers as they navigate funding sources, support services and legal issues (such as guardianship) we can help overcome barriers. Often, in the case of ASD, follow-up tends to be sporadic, fragmented and crisis-oriented. Early planning must also be accompanied by regular, ongoing follow-up across the lifespan (much like persons with a chronic health condition such as diabetes).

The Launch program, an initiative of The Sinneave Family Foundation, is focused on discovering personal strengths and areas for growth based on an individual's interests, abilities and needs. It offers training and navigation support to individuals and their families to help create Individualized Transition Plans which are created by answering three key questions: (1) Where are we now? (Assessment), (2) Where do we want to go? (Goal Setting), and (3) How do we get there? (Implementation). In addition to this Guide, many resources (including training videos, assessment and planning tools) are available online.

For more information email: launch@theabilityhub.org.

Launch Domains

We encourage parents of children with ASD to recognize the broader context in the transition from adolescence to adulthood. There are many areas of functioning, beyond health issues and/or school performance, that are also important and require your attention and support. To maximize opportunities for successful and independent adult living, consider your child's level of functioning as well as the level of knowledge in the following five domains:

- * Health and Well-Being
- * Education and Employment
- * Communication and Social Relationships
- * Independent Living Skills and Self-Advocacy
- * Legal and Financial Issues

Start Early

It is critical to begin the transition planning process as early as possible – ideally when your son/daughter is 13 to 14 years of age. By starting early you will allow yourself more time to prepare and implement a plan that will effectively address the challenges of preparing for adulthood. Some transitions are linked to certain time frames or are related to health care, schooling options and the age of majority (18 years in Alberta).

It's Never Too Late

Making positive changes for young adults with ASD can be done throughout adolescence and into early adulthood. Not all families are able to make specific transition tasks happen exactly when they would like them to occur. For example, some young adults with ASD may have graduated from high school and continue to live at home, however they are not actively engaged in their community. Others may not have had success in finding a job or may not be attending post-secondary education and, as a result, have very few activities to participate in during the day. Medical issues may also interfere with, slow down or fragment the transition planning process. No matter when you start, or how old your child is, the transition planning activities and resources in this Guide will be valuable to you.

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Welcome

This Guide is intended for parents of adolescent children with Autism Spectrum Disorder (ASD) who wish to better understand the process of navigating the transition between the teenage years and young adulthood. It was inspired by the courage and positive spirit of all families who support the growth and development of their sons and daughters with ASD.

Many autism resources are focused on the early years, and elementary-aged children. As these children move into junior high school, high school and beyond it seems there are fewer resources available. This Guide was developed in response to the need for more clear information and practical guidance on the transition from childhood to adult living. It addresses a range of issues specific to the teenage years and provides fact-based insights on the key considerations and major timeline events for this part of the developmental journey. While the teenage years can be challenging for any parent, it is important to be positive and to know that help is available.

Who is This Guide For?

The primary audience for this Guide is the parents of adolescents with ASD and their family members. The material is also relevant for legal guardians, caregivers, and professionals who work in schools or clinical settings with teenagers and young adults with ASD. However, to simplify the language used in the Guide, going forward we will use the word “parent” as a general term that represents all of these interested groups.

Organization of This Guide

The primary material in this Guide is organized into the five Launch domain areas. In addition to this information, we have created several other supports:

- * Video Modules - Created to help you better understand the key points of transition planning and the five key domain areas featured in the Guide.
www.theabilityhub.org/initiatives/launch/launch-domains-and-videos
- * Transition Planning Timeline
- * Resource Appendix - Find specific programs, services, organizations, websites, books and other useful resources. Many of these resources are also available through the Resource Centre at The Ability Hub and www.theabilityhub.org.

We are optimistic that you and your child can embrace the material to create safe and meaningful learning opportunities and life experiences during this important phase of life.

Information About Your Child

Name: _____

Age: _____ Date of Birth: _____

Address: _____

Phone: (Home): _____ (Mobile): _____

Allergies: _____

Medical Conditions: _____

Current Medications: _____

Physician Name: _____

Physician Phone: _____

School: _____ Grade: _____

Hobbies: _____

Talents/Skills: _____

Likes: _____

Dislikes: _____

Strengths: _____

Emergency Contact Name: _____

Emergency Contact Phone Number: _____

Facts About Autism Spectrum Disorder

Autism is a lifespan disorder that will affect an individual long after childhood. This part of the Guide presents fact-based general information about Autism Spectrum Disorder. It examines the definition, prevalence, related difficulties and interventions.

Autism Spectrum Disorder (ASD) Defined

New Diagnostic Criteria for ASD

In May of 2013 the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published by the American Psychiatric Association. The diagnostic criteria has been modified and the diagnosis will now be called Autism Spectrum Disorder (ASD) without the previously used subdiagnoses (Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Disintegrative Disorder).

The new diagnostic criteria has been rearranged into two areas: 1) social communication/interaction, and 2) restricted and repetitive behaviours. A diagnosis of ASD will be based on symptoms (currently or by history) in these two areas. Although symptoms must begin in early childhood, they may not be recognized fully until social demands exceed capacity. Symptoms must cause functional impairment and not be better described by another DSM-5 diagnosis.

All of the following symptoms describing persistent deficits in social communication/ interaction across contexts (not accounted for by general developmental delays) must be met:

- * Problems reciprocating social or emotional interaction, including difficulty establishing or maintaining back-and-forth conversations and interactions, inability to initiate an interaction, and problems with shared attention or sharing of emotions and interests with others.
- * Severe problems maintaining relationships — ranges from lack of interest in other people to difficulties in pretend play and engaging in age-appropriate social activities, and problems adjusting to different social expectations.
- * Nonverbal communication problems such as abnormal eye contact, posture, facial expressions, tone of voice and gestures, as well as an inability to understand these.

Two of the four symptoms related to restricted and repetitive behaviour need to be present:

- * Stereotyped or repetitive speech, motor movements or use of objects.
- * Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change.
- * Highly restricted interests that are abnormal in intensity or focus.
- * Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment.

Symptom severity for each of the two areas of diagnostic criteria is also defined. It is based on the level of support required for those symptoms and reflects the impact of co-occurring specifiers such as intellectual disabilities, language impairment, medical diagnoses and other behavioural health diagnoses.

Because almost all children with DSM-IV confirmed autistic disorder or Asperger syndrome also meet diagnostic criteria under DSM-5, re-diagnosis is not necessary. Individuals may wish to continue to self identify as having Asperger syndrome, although the DSM-5 diagnostic category will be ASD.

Prevalence of ASD

ASD is not rare. Current studies estimate that 1 in 68 children will be diagnosed with ASD (Center for Disease Control, 2015).

Experts disagree about whether there has been a true increase in the prevalence of ASD over the last several years or whether the guidelines for clinical diagnosis have changed to allow for more symptoms to meet the criteria for having ASD. Today, many more parents and doctors know about ASD; parents are more likely to take their children to be diagnosed and doctors are more able to properly diagnose. These and other changes may help explain some of the increase in prevalence over the last few decades. Even so, more children are being diagnosed now with ASD than ever before.

One consistent finding in the research is a gender difference. The ASD risk for boys is four to five times higher than for girls.

Getting Ready To Launch: Transition Planning

This section of the Guide provides you with an introduction to the concept of transition planning and the role of the parent. It examines key life changes and age-period transitions common to adolescence. Prepare to launch your son or daughter into adulthood.

Your Role as a Parent

You have tremendous hope for your child as he/she moves through their teenage years. You wish for good health, safety, and happiness, for them to have the ability to develop meaningful relationships and for continued positive growth and development. As they become young adults you may also hope that they are able to make good choices and that they can live as independently and productively as possible. The many physiological, psychological, and social changes that naturally occur during adolescence are even more difficult for some individuals with ASD who may already be resistant to change. Therefore it is best to start early, be prepared, and have a “team” of supportive people to help you with transition planning.

Key Transitions

Some of the key transitions that can take place during the transition from adolescence to adulthood include:

- * A change in service providers or caregivers
- * A change from one support program to another
- * Younger siblings mature and surpass their brother or sister with ASD in certain capabilities
- * A change in the parents' role from adolescence to adulthood
- * Onset of puberty, hormonal changes, dating and sex
- * The transition from junior high school to high school
- * The transition from high school to employment
- * The transition from high school to vocational training or post-secondary education
- * The transition from living in the family home to living more independently (in private or shared accommodation)
- * The transition from paediatric health services to adult health services

What is Transition Planning?

Developing a successful transition plan is an ongoing process. It is a partnership between the individual with special needs, their family, local service providers, school personnel and government staff who support youth who are transitioning to adulthood. Transition planning can help identify opportunities to engage in experiences during the high school years (or earlier) that will help individuals better prepare for their future.

As your child transitions from childhood to adulthood they must make some important decisions about their future. They will be faced with making decisions about future living arrangements, further education, employment, managing income and finances, community engagement and social relationships. Careful timely transition planning can help proactively manage these complex issues.

An Individual-Centered Approach

Transition planning provides an opportunity to review personal accomplishments and create an individualized vision for the future. A fundamental part of this process is to consider your adolescent's unique needs and their dreams. Successful transition approaches focus more on strengths and abilities than on limits and disabilities. Creative

thinking is a huge part of this process and you may have to adjust parts of your dream to match with what is practical and available in your community. To get started, you might want to consider these questions about what makes your adolescent unique:

- * What makes your adolescent most happy?
- * What are his/her strengths and skills?
- * What obstacles to a successful transition exist?
- * What personal skills are needed to make the transition smoother?

Transition Team

Other people who know and care about your adolescent can form a supportive network. They can help you create a workable plan to make your adolescent's dream for a happy future come true. Together you can identify what needs to be done now and what can be accomplished in the near future; you can generate ideas, ask questions and attend workshops and conferences to develop a transition plan that captures the strengths of your adolescent and that helps build the meaningful life that he/she wants.

Transition Team Members

TEAM MEMBER	CONTACT INFORMATION

Transition Priority Checklist

As your child reaches each of the transition points between adolescence and adulthood, it is important to determine both short-term and long-term priorities and areas of concern. All parents want to see their children succeed in life, to be happy and to be as independent as possible.

The transition planning process encourages you to understand not only where your son or daughter's strengths lie but also where opportunities for growth and development may exist.

Take time to fill out the following priority checklist with your adolescent.

Transitions

What transition(s) is your son/daughter currently experiencing? Please check all boxes that apply:

- Puberty
- New school/new program
- Junior high to high school
- High school to employment
- High school to vocational training
- High school to university or college
- Independent living
- Other _____

Ratings

On a scale of 0-3 please rate how important each of the following concerns are for your son or daughter within the next 6 months.

0 = not important

1 = somewhat important (but not a priority this year)

2 = important source of concern (to be addressed in the upcoming year)

3 = very significant source of concern (to be addressed within the next few months)

	0	1	2	3
Behaviour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dependency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Initiative	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment opportunities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work experience opportunities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships with peers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disengagement/ withdrawal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educational support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vocational and training support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational/ leisure activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daily living skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motivation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (Please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Priorities for the next 6 months:

1. What area(s) would you most like to target over the next 6 months?

2. What would you consider to be an indication of progress in each of the areas?

3. Where would you most like to see your child show greater independence and/or reduced reliance on others?

This Guide will describe each of the 5 domain areas. At the end of each section write down one or more goals that you would like to begin working on. By the end of the Guide you will be able to create an Individualized Transition Plan for your adolescent. A blank copy is included at the end of the Resource Appendix.

Launch Domain #1: Health And Well-Being

Address key aspects of health relevant to adolescence and young adulthood. Important considerations in this domain include:

- Managing one's health care needs
- Understanding health conditions
- Scheduling medical appointments
- Medication management
- Recognizing the need for medical attention
- Healthy eating
- Physical fitness
- Dental care
- Sexual health
- Mental health

Physical Health and ASD

Ensuring that your adolescent has his/her own general practitioner once they can no longer access the services of a paediatrician is part of the transition planning process. Families must plan for the transfer of care from the paediatric provider to a new provider who works primarily with adults as patients. This is an opportunity for your son/daughter to build a relationship with a family practitioner and in the process foster more personal responsibility for his/her own health care.

A proactive approach to health care can help alleviate some fears associated with health issues and provide a better overall understanding of self-care activities. Your physician can help identify health-related concerns, and develop a plan for how to handle medical emergencies. Your son/daughter should be aware of the impact certain behaviours can have on their health to ensure they make informed decisions.

Adolescents with ASD can have a wide range of physical health disorders. Some of the most common are in areas of sensory sensitivity, sleep, seizures, and digestion. Despite this range of health issues, many health professionals do not have specialized training or knowledge about autism and have difficulty diagnosing, understanding, and treating patients with ASD. For example, some individuals with ASD may have been misdiagnosed as having other disorders, such as attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD) or oppositional defiant disorder (ODD). Thus, parents can strive to better educate their doctors and other health professionals concerning ASD issues.

Healthy Eating

Many teenagers, including those with ASD, consume foods that are high in sugar and fat. Limiting “junk food” and replacing it with healthy snack foods, fruits and vegetables, is the best way to promote good health. Some medications for anxiety, depression and seizure control may also increase appetite. If your son/daughter is taking prescription medications, both of you need to be aware of potential side effects of the drugs such as weight gain. Individuals are most at-risk for developing eating disorders, such as anorexia or bulimia nervosa, during their teenage years. Thus, it is important for you to encourage your adolescent to eat a balanced, nutrient-rich diet to promote their long-term overall health.

Physical Exercise and Fitness for Health

It is important to establish a daily routine for your son/daughter; one that includes physical activity. Regular exercise can provide your child with many health benefits. Plus, physical exercise is a great way to manage stress or anxiety. If your child is interested, participating in a team sport has the added benefit of social interaction and the potential for making new friends. However, if being involved in a team sport is not of interest to your son/daughter, there are a wide variety of exercises that can be enjoyed individually or in small groups, including:

- * Biking
- * Jogging
- * Jumping rope
- * Skating
- * Skiing
- * Swimming
- * Walking
- * Yoga
- * Meditation

Dental Care

Making and maintaining a dental care routine is an essential part of ensuring good oral health. Your adolescent should be brushing at least twice a day and flossing at least once a day, if possible, to prevent tooth decay and gum disease. Regular visits to the dentist's office are also a crucial part of maintaining good overall oral health.

It is important for you as a parent to develop a good relationship with your child's dentist and the dental office staff because collectively they are an important part of the health care team. As with other health care providers, it is critical to maintain open communication through the transitional years and encourage your adolescent to take more personal responsibility for attending dental appointments and communicating directly to the dentist themselves (if he/she is able).

Sexual Health

Discuss sexual development and physical changes associated with puberty with your child as early as possible, preferably before physical changes occur. Many incorrect stereotypes exist about people with disabilities and sexuality, which can make it difficult for health workers and parents to discuss these important issues. Families need to give themselves permission to talk about sex and dating rather than avoid the issue.

In addition to being taught about human sexuality and contraception, your adolescent should be given the opportunity to speak with a health professional about how to avoid unsafe sexual activity, including relationships that may be exploitative or abusive.

Mental Health and Addictions

There is a growing awareness that young people with ASD are at increased risk of developing a range of mental health issues. About half of adults with an autism spectrum condition also have mood or anxiety disorders.

Because additional mental health difficulties are common, continuity of medical care and mental health service care is important. There is often limited access to mental health and community care services for adults with ASD, which poses a challenge for families to find and engage with mental health care providers in their local area.

Symptoms of mental health issues often emerge in adolescence. Recognizing the symptoms can help parents identify the need for a professional mental health assessment for their son/daughter. Discuss concerns with your child's medical doctor and, if possible, request that someone with experience in both ASD and mental health see your child.

Common Mental Health Disorders Among Adolescents With ASD

Mental health issues that affect young adults with ASD include Anxiety, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Depression and related Mood Disorders. It is possible that an individual with ASD may also be suffering from a co-morbid undiagnosed mental health condition that needs to be addressed.

Anxiety

Many adolescents with autism, as well as their parents and teachers, identify anxiety as a characteristic associated with autism. Similar to many adolescents who are not on the ASD spectrum, individuals with autism may experience additional anxieties related to a variety of sources, including: an inability to express oneself, difficulties with processing sensory information and a high need for predictability. Roughly 1 in 3 individuals with ASD also meet DSM-5 criteria for one of the specific anxiety conditions. The most common anxiety diagnoses among those with ASD include:

- * Phobias or fears (44%) — fear of specific objects, activities, or situations (e.g., heights, insects)
- * Social anxiety (29%) — fear of being negatively evaluated in social situations.
- * Generalized anxiety (13%) — persistent, excessive, uncontrollable anxiety/worrying.
- * Panic disorder (10%) — recurrent panic attacks that are not associated with any specific stimuli.

Attention Deficit Hyperactivity Disorder

ADHD may be the most common co-occurring psychiatric disorder among children with ASD, occurring in approximately one-fourth to one-half of cases.

Obsessive Compulsive Disorder

OCD is also very common, although rates in individuals with ASD have varied across studies from approximately 1 in 10 people to more than 1 in 3 people. However, by definition some level of compulsive behaviour is found in the majority of individuals with ASD.

Depression and Mood Disorders

Depression and mood disorders can also affect adolescents with ASD. Making a formal diagnosis of depression can be complicated however, as common characteristics of ASD, such as social withdrawal, appetite and sleep disturbances, are also core symptoms of depression.

Dual Disorders

If an individual with ASD has one mental health disorder, it is likely that he/she will meet criteria for having a second mental health problem as well, which we refer to as dual disorders or co-occurring disorders. A range of mental health disorders is commonly seen as dual-disorders in ASD, including: ADHD symptoms, anxiety disorders, OCD, Oppositional Defiant Disorder, Phobia, Depression, Bipolar Depressive Disorders, Psychosis Not Otherwise Specified, and Schizophrenia. Other health issues can include substance abuse, stereotyped mannerisms, sleep problems, tics and Tourette's disorder, and seizure disorders. Unfortunately, having more than one mental health disorder at the same time is something that can often be overlooked by doctors. Therefore, it is important to be aware of this possibility and have a thorough assessment done if problems are observed in one area so that other potential disorders can be identified. Having multiple mental health issues can have serious negative consequences on school performance and overall quality of life. Accessing and receiving appropriate medical and psychiatric treatment is critical.

Smoking, Substance Abuse and Other Behavioural Health Addictions

Youth with ASD are not immune to normal adolescent interest in trying addictive substances. The rate of adult use of alcohol and tobacco is high, which means the modelling of use and access to these substances is open to many adolescents with ASD. National surveys of Canadian adults show that roughly one in every four adults is affected by physical and psychological attachments to using certain substances (e.g., tobacco, alcohol, illicit drugs, prescription medications) or they engage in compulsive behaviours (e.g., gambling, video games, sex, eating, computer use).

Addictions can be dangerous for anyone, but someone with autism may face more risk when they try drugs or alcohol. ASD often affects judgment and the ability to accurately assess risk. Adolescents with ASD often do not have the social skills, insight, organization or understanding of what is appropriate behaviour in a given context. Once developed, addictions are often resistant to change and require treatment and support for many years – not unlike other chronic health conditions. Thus, it is critical to pay attention

to risk factors for addiction during the teenage years when young people may be experimenting with substances. Early intervention can help prevent substance abuse or behavioural addiction issues from getting worse.

Treatment Issues in Health Care for ASD

Finding a Family Physician

If your adolescent is seeing a paediatrician they will need to find a family physician to take over their health care needs by the time they are 18 years old (or shortly thereafter). Usually family physicians are able to effectively manage the health care needs of individuals with ASD. However, some people with ASD have difficulty finding a primary care physician. Paediatricians may refer their 18 year old patients to family physicians or families may have to do this task on their own. It may take time to find a family physician your child feels comfortable with and trusts. It also takes time for the family physician to get to know your child and your family. This is a very important relationship that should not be underestimated.

Many individuals with autism are reluctant to see a medical doctor or other health care professional. This means diagnosis and treatment of minor conditions can be delayed to the point where they become far more problematic. For this reason it is important for parents to encourage regular medical care from providers and for them to discuss with staff (in advance) how best to minimize the sensory stimulation of a doctor visit. For example, a visit to the doctor could be scheduled at the start of the day to ensure there is no waiting in the office prior to the visit. Or, visits could take place in quiet rooms that have less intense lighting.

Treatment Issues for Mental Health

A lack of knowledge combined with the social stigma and negative stereotypes about mental health disorders can result in teenagers with autism having mental health concerns that go undetected or untreated. This can have profound consequences for the health and well-being of the individual with ASD and his/her family. Autism is a complex disability that can make it harder to diagnose mental health disorders. It is a condition that also can make it more difficult for health care professionals to develop successful, trusting relationships with adolescents, and requires services to be adapted to the individual patient. As a consequence, mainstream interventions (if unadjusted for the unique needs of young people with ASD) may fail to improve the mental health of a young adult with autism. Thus, it is important to disclose ASD status to health care professionals when seeking help for mental health concerns.

Psychiatric Medications

Many medications that are effective in treating mental health symptoms and behaviours associated with ASD were developed for other, unrelated conditions. Symptoms such as disrupted sleep or appetite, increased anxiety, or increased aggressive behaviour may be addressed through the use of medication. Medication therapy may be helpful to improve symptoms and behaviours associated with performance in school, the ability to tolerate change, and the ability to get along better with family members and peers. Families should be clear about what they want to see improved through medication. Improved performance in school, improved ability to tolerate change, or to get along better with family members and peers are examples of behaviours or symptoms medication therapy can be applied to. It is important to remember that each adolescent will respond somewhat differently and some medications will be effective for some individuals but not for others.

It is important to communicate changes in mood, behaviour or reactions to medications that you observe with your child's physician or psychiatrist and also to be patient with the process. New medications often take time to establish their effectiveness and may not take effect right away.

As your adolescent develops more independence he/she needs to be aware of the potential side effects of each medication prescribed. It is important to bring new symptoms to their physician's attention or tell a family member who can assist with the communication between the physician and the individual. Families need to continue to monitor their young adult's health/behaviour as well. Many of the psychiatric medications can lower the seizure threshold and/or cause negative behavioural changes. Some side effects of medications can look like mental health issues (i.e., hallucinations, an increase in obsessive tendencies, or mood changes). Changes in eating behaviours and appetite are also common side effects of some medications. After your child starts a new drug, be sure to report any changes in behaviour or new symptoms to the prescribing physician.

Medication Adherence

Adherence to medications is often an issue during adolescence as there can be unpleasant side effects with some drugs. This may interfere with the goal of taking them on a regular basis as intended by the doctor and problems are likely to arise if there is a lack of consistency and care in which prescription drugs are taken. The period of adolescence also involves many physical and hormonal changes that may alter how the drug works or interacts with other medications. Therefore, both the parents and young people with ASD should have frequent conversations with their doctor or psychiatrist about the proper use of medications.

Self-Advocacy in Health Care Settings

Young people with disabilities and special health needs related to ASD should attempt to manage their own health care and learn how to work more effectively with health professionals as partners in their own care. Specific health care self-advocacy actions include performing routine self-care activities, scheduling doctor's appointments, understanding a health condition, recognizing when symptoms need medical attention, taking medications as prescribed, and everyday goals for nutrition and physical exercise. Transferring the responsibility for health care from the parent to child can be a complex process. It requires assessing a variety of factors, including the complexity of one's health needs, his/her physical and cognitive abilities and degree of self-determination, as well as family factors. Cultural factors such as values, health care practices, and beliefs about disability must also be considered.

Goals to Work On (Health and Well-Being)

1. _____
2. _____
3. _____

Launch Domain #2

Education And Employment

Choosing the right kind of post-secondary education setting, employment training program or job can seem like a daunting task. In this section of the Guide you will find tips to support the transition from high school to post-secondary education or to vocational training programs, and advice on determining whether or not an educational program will be a good fit for your child.

Key issues covered in this section include:

- Finding the right school and/or program
- Types of post-secondary schools and programs
- The IPP and post-secondary planning
- Vocational training
- Finding the right job
- Workplace accommodations

Education and Academic Achievement

Parents devote a great deal of time to finding the right education program for their child and helping their children to be successful in school. Ideally, parents are able to work closely with teachers and other professionals affiliated with their child's school to set appropriate learning goals and to ensure that educational programs are individually tailored to achieve these goals. Usually program goals are written in the form of an Individualized Program Plan (IPP) or Individualized Education Plan (IEP) that is reviewed and updated regularly. Beginning around age 13, the focus of educational services should not only address academic goals but also focus on identifying and developing practical life skills. Students should be included in this process as often as possible and transition planning should begin well in advance of graduation from high school.

Many parents find that once the structure and regular routine of a school program ends, the absence of meaningful activities during the day leads to problem behaviours arising.

If post-secondary education is a goal for your young adult you may want to help identify his/her academic strengths to better determine a match between interests and a particular school or program. A variety of assessments are available to help understand how your son/daughter performs in different areas. There are many kinds of tools that can be used in high school when preparing for transition including psychological, vocational and functional assessments. Information from these types of assessments can also help determine whether your child qualifies for funding to help support educational or vocational training programs and what type and level of support may be required to be successful.

Testing performed by a psychologist or other professional may be required in order to apply for funding and program supports after your child turns 18. For example, some provincial programs require an IQ score of 70 or below in order to qualify for services. Adaptive behaviours and daily living skills assessments can help to determine the type and amount of support an individual with ASD may need, whether it be support in the form of home-based support services, special education and vocational training for young people, supported work or special living arrangements such as personal care attendants.

It is important to determine if your child will require an updated cognitive or adaptive behaviour assessment, and have those assessments completed prior to leaving the school system. A psychologist can measure cognitive abilities and will typically include an estimate of IQ and adaptive functioning in their assessment to assist in determining which support programs your child is eligible for.

Issues in Post-Secondary Education

Begin exploring different post-secondary programs while your child is still in high school. Help your child look into potential summer courses at a university/college or explore other options, such as technical or trade schools in your area. Meet and network with current students and attend any information meetings that are offered.

In order to make the best decision about a program or university it is helpful to explore what services they offer to help your young adult with ASD. Find out what types of disability-related services they offer to students and what the process is to access

resources and accommodations. By becoming familiar with the system and the services provided your young adult will be more adequately prepared to advocate for himself, increasing their chances for success.

Here are some specific activities to consider when selecting a school:

- * **School Visit:** Arrange for your adolescent to visit the school on a number of occasions, if possible. If your adolescent is particularly resistant to change it may be necessary to introduce these new aspects slowly and go through a process of desensitization and rehearsal. For example, the initial visit may need to be devoted to going to the new school and walking in the front door. On another visit you might visit a classroom, then the gymnasium and later other classrooms. Try to get a locker in a location your adolescent is comfortable with, taking their sensory needs into account (if possible). Practice travelling from the locker to different classrooms.
- * **Peer Mentor:** Identify key people who would be available for your adolescent when they have questions or need advice. Identify these individuals ahead of time and enlist the help of peers who may be able to assist your adolescent in making adjustments to the new school; those who may be able to accompany your adolescent to various locations in the school.
- * **School Video:** Another way to support your adolescent is to create a videotape of the new school to help your child prepare for their new venue.
- * **Orientation Day:** Attend orientation days and facility tours. This will help identify potential supports (such as peer mentor candidates) and also identify potential challenges such as anxiety triggers, which can then be addressed in advance through the use of social stories.

Profiles of Post-Secondary Educational Options

Many adolescents (with support from their family) want to go on to post-secondary education, but do not know where to begin. A first step is to find out what types of support programs exist, what school environment will be the best match for your adolescent, academically, geographically, socially, and in relation to his/her independent living skills. It is important to keep an open mind, think creatively and do your research. Individual needs and abilities will differ. The post-secondary experience may present some unique challenges for those with ASD and perhaps your adolescent may want to begin with a small local college or a specialized training program. Some schools may allow a student with interest in one particular subject to only take one class at a time, to audit classes or take coursework online.

Four-Year College or University

More and more educational settings provide support services for students with disabilities. However, students and their families are encouraged to research this carefully to make sure that the supports offered meet the needs of their adolescent. Students with autism may need assistance learning the advocacy skills required to ask for supports and accommodations. A counsellor, peer counsellor, academic strategist or someone from the school's office of disability studies may be able to assist with this.

Community College

Several community colleges are developing programs to meet the needs of young adults with developmental disabilities. For some students this may include programs focused on teaching life skills like money management, and daily living skills. For others it may be more academic programs - or a combination of both. Most community colleges recognize the needs of individuals with developmental disabilities and tailor programs for these students.

Vocational or Technical Schools

Vocational or technical schools can provide individuals who have disabilities the opportunity to experience hands-on learning in a variety of fields. There are some career and technical education programs that provide hands-on training along with academic skills such as reading, writing, math and problem solving skills. These programs also provide workplace experience such as internships and mentorships.

Participating in vocational or technical classes during the last two years of high school, especially classes that offer occupational-specific instruction, can be a successful transition strategy. It may be helpful to work with your school district to find out about programs in your area. Even for those who may not want to attend college full-time, or those who do not possess the standard high school diploma, young adults with autism do have the ability to audit many classes at vocational or technical schools. Auditing a class can be a useful way to learn more about the topic without having to take the class for credit and be required to fulfill all of the requirements.

Inclusive Post-Secondary Education (I.P.S.E.)

Some educational institutions offer programs for students who would not be able to compete academically in a degree or diploma program, but would benefit from attending school in an inclusive setting. Educational support workers assist your adolescent in completing modified requirements for the program or courses. At the end of a 2 or 4-year program students receive a certificate of completion in the program.

General Education Diploma (G.E.D.)

Students who did not complete their full high school diploma requirements may also opt to study to obtain their general educational diploma. The G.E.D. can be attained through community colleges or by taking the required courses on-line.

Support for the Post-Secondary Academic Environment

Involving parents in the education of elementary and secondary school students is widely encouraged. However, once adolescents with ASD graduate from high school the resources and guidance available to parents become more difficult to find. As a parent you will continue to be an important role model and advocate for your son or daughter and a key part of the support network they will need to be successful in the post-secondary environment.

Here are some suggestions for getting the support your young adult needs while at college or training school:

- * Provide key people at the college (i.e., professors, counsellors, residence hall assistants, etc.) with information about ASD and how it affects your young adult. Include a description of some of the particular challenges he/she faces and what kinds of strategies can be used to assist him or her. Developing a one-page “fact sheet” about ASD and your young adult may also be helpful to distribute to key people at the school.
- * Locate an understanding guidance counsellor or student services staff member who can advocate for your young adult. This support may come by providing information about services on campus, introductions to groups with shared interests, and recommendations of professors who may be more willing to provide assistance and accommodations.
- * Suggest that your young adult use the same strategies for learning that were effective in high school such as written schedules, visual aids, tape recording lectures, and other practical accommodations.
- * Discuss the options for taking exams in quiet settings that are free from distractions. Modifying exams based on your young adult’s particular needs, specifically allowing for extended time to write exams or writing exams on a computer versus hand-writing may also be possible.
- * Investigate organizations on campus with which your adolescent may have a shared interest (a club for computer gamers, for example). This may be a place where he/she can meet a trusted peer to assist with navigating school life.

If post-secondary education is a realistic goal for your child, getting further education or training will open up a whole new realm of possibilities for the future. Taking the time needed for advance preparations and planning can make this process go more smoothly and successfully.

Self-Advocacy in Higher Education Settings

Once your child is accepted into university or a post-secondary training program they should begin to take over the role of advocate from you. In fact, self-advocacy skills are considered so critical to your child's success in post-secondary education that many such institutions do not even have a mechanism by which you, as the parent, may advocate on their behalf. As such, it is of critical importance that you prepare your child with self-advocacy skills to help them communicate their needs to the appropriate person in the appropriate manner. Note that many universities have an office of "Disability Support Services" or "Accessibility Services". Begin to promote effective self-advocacy by reviewing the types of services and supports that were useful in high school, and explain how they might still be beneficial in this new setting.

The IPP and Post-Secondary Planning

The first step for any student with an IPP is to contact their post-secondary institution's disability resource centre. The student will be assigned an advisor who will help them with any accommodations or academic support they may require while attending school. Students will need to provide an updated copy of their grade 12 IPP and a recent psychoeducational assessment or medical documentation. It is important to remember that accommodations will not automatically be offered at a post-secondary institution. The student has to meet with an academic advisor to submit their request.

Vocational Training and Work Opportunities

Having a meaningful job can not only provide financial independence, but often forms an important part of one's social network and feeling of self-worth. However, adults with autism are significantly underrepresented in the labour market. In fact, recent studies show that as few as 1 in 8 ASD young adults are able to get a paid job with a living wage. A study from the United States in 2012 found that about half of young adults with ASD were able to get jobs after high school, but the other half had no participation in employment or further education.

The Role of Job/Volunteer Experience in Adolescence and Young Adulthood

Too many individuals with ASD graduate from high school without internships or any work or volunteer experience and, as a result, face great difficulty obtaining or maintaining a paid job in their chosen field. This is because hiring practices are often influenced by prior work experience. Early exposure to work is a critical step towards getting and keeping a job, and progressing in one's work and/or career path.

In order to help a young person explore work-based learning outside of a school setting there are creative ways to combine community relationships, a young person's interests and family or personal networks. The majority of job opportunities are gained by using personal contacts. Using one's personal network in a job search can be highly effective, and it is one way that family members can contribute to successful employment outcomes for their son/daughter with ASD. Relatives, friends, co-workers and people who own or work at businesses regularly patronized by a family may have potential job leads. This method can also help identify safe and familiar work site locations. Proactively notifying friends and acquaintances about the job search will prompt them to think of you and your child when a job opportunity arises.

Other strategies to increase work readiness include: assigning responsibilities at home, job shadowing with friends or family, encouraging your child to volunteer in the community, or to volunteer in a family run or local business. Your child can also self-advocate when seeking a new job experience by connecting with others who have already entered the job market. Part-time jobs, unpaid internships and volunteer experiences while in adolescence can lead to better future employment as a young adult. When putting together a resume these experiences and interests should be highlighted.

Finding the Right Job

As you support your child with finding the right job it is important to consider the compatibility between the individual and a particular job's social, navigation, and production requirements. This "job match" is the extent to which a particular job meets an individual's needs in terms of challenge, interest, comfort, camaraderie, status, hours, pay and benefits. Depending on the strengths, interests and support needs of your child there are a variety of different types of work environments to consider.

Supported Employment. Individuals with autism work in competitive jobs alongside other non-ASD individuals, although the ASD-person receives on-going support services while on the job. Typically, this type of support is offered by universities, hotels, restaurants, office buildings, or small businesses.

Self-Employment. This involves matching an individual's interest and strengths to a product or service that can provide some income. For some this can offer more flexibility when tailoring the work environment to meet the needs of the individual, and when customizing the job (or a portion of the job) to the strengths of an individual.

Secured or Segregated Employment. Individuals with ASD work in self-contained units and are not integrated with workers without disabilities. These job placements are usually organized by disability employment agencies that place small groups in an employment setting, where typical job tasks include collating, assembling, or packaging.

Workplace Accommodations for ASD

When applying for a job it is important to consider when and if your young adult will disclose that he/she has ASD. Disclosure is a personal choice and there is no law obligating anyone to disclose that they have a disability. If your child chooses to disclose, then information about ASD should be provided to both the employer and co-workers. This will allow them to offer support when necessary. Be sure to emphasize areas where he/she needs help, along with his/her particular strengths.

Employers are required to make workplace accommodations for individuals with disabilities if it does not impose an “undue hardship” on the operation of the employer’s business. Often small and low cost accommodations are possible and can make all the difference to becoming a successful employee. Many youth with significant disabilities use job coaches and assistive technologies in the job setting. These formal supports can be provided or funded by service providers from special education, local social service agencies, waiver programs, vocational rehabilitation, or developmental disabilities systems.

Cognitive Function

In order to address difficulties with cognitive functioning accommodations may be considered. Individuals with ASD may have difficulty with organization, attention and mental planning. This is referred to as difficulty with “executive functions” and can impact the ability to learn and to perform a job or task, even when skilled at the task. Difficulties with “executive function” can cause the person to want to do a job differently than the supervisor or job coach presents it. Indication of executive function challenges may appear as:

- * Being overwhelmed by seemingly “simple” tasks
- * Difficulty getting started or knowing what to do when finished
- * Being easily distracted or having difficulty re-engaging with the task or activity
- * Viewing a simple problem-solving situation as insurmountable
- * Having a messy or disorganized work area, even if the individual desires routine and predictability

Repetitive Behaviours and Routines

Individuals with ASD can demonstrate ritualistic or repetitive behaviours ranging from physical routines and verbal repetition to topical restrictions. In some situations, these behaviours or interests might interfere in the workplace. In other situations, they can be an asset if tasks need to be repeated frequently as part of the job requirement (provided that these activities are interesting or enjoyable to the individual). Repetitive behaviours may be more obvious when adjusting to new settings as the rigid behaviour

may intensify. Requirements of the new job may not easily align with the individual's established routines. Patience and support can lead to adjustments that work for everyone. Adjusting to change is often difficult. Many people with ASD avoid or resist change because of the anxiety associated with the unknown. Adjusting to changes in routines, people, jobs, materials and so forth may take more time and preparation for the individual with ASD than for other employees.

Visual Routines

Make visual routines and checklists (words or pictures) of frequent routines available if they are helpful. Routines to consider include:

- * Arrival and departure routines
- * Break or lunch activities
- * Job routines (a person may have several jobs that can be reflected in a step-by-step visual routine)
- * Template/diagram for organization of work area (e.g., photograph of desk organization)
- * Templates or “jigs” that assist a person in completing a task by offering a visual “road map” throughout the task (some templates provide an example of each step of the task)

Calendars and Timelines

Post and review calendars or timelines of deadlines, important tasks, holidays and other aspects of the work or the schedule. Break down a long-term task/assignment into planned steps over the course of several days/ weeks/months with a timeline.

Timers

There are many types of timers available. Some are visual while others include an auditory cue. Choose a timer that works best for the individual.

Smartphone and Computer Apps

There is an App for almost every type of visual support, including: calendars, routines, schedules, timers, choice boards, reminders, etc. Many Apps include pictures, words and voice outputs that are easily customizable.

Social Supports at Work

Both you and your son/daughter should be aware of natural supports in the workplace. Natural supports include training, job sharing, mentoring and flexible scheduling. An example of a natural support is when a more experienced employee helps a co-worker solve a problem. Natural supports are provided directly by the employer (not an outside agency) and may also be available to employees without disabilities. Natural supports are appealing to employers because they are generally low cost. They are also appealing

to people with ASD and their families because they promote normal interaction and relationships with co-workers. It may require some effort to find the right situation for a person who needs extra support on the job, but for a person with disabilities, natural supports can help increase the feeling of accomplishment and independence on the job. Employees with ASD who receive natural supports from co-workers are more likely to have a more typical work role, higher wages and positive relationships at work.

Options Other Than Employment

Some individuals with autism (and their family) may feel that employment opportunities are not right for them at the present time. There are other options that can be considered: volunteering at school, church or in the community, or becoming a mentor to other younger people with ASD. Whatever path is taken after high school, including some form of community engagement and regular interaction with others outside of the family home or independent living situation is beneficial and should be encouraged.

Goals to Work On (Education and Employment)

1. _____
2. _____
3. _____

Launch Domain #3: Communication And Social Relationships

This part of the Guide addresses knowledge and demonstration of proper oral, written and nonverbal communication skills. Such skills include, exhibiting appropriate behaviour in public contexts, communicating clearly and kindly with family and friends, and communicating effectively at work. Basic skills are also needed for interacting with others at school and in the local community. This area also concerns the ability to develop and maintain personal relationships with other people, including family members, friends and romantic or sexual partners. Another opportunity for social relationships is engaging with others in leisure activities and various forms of recreation. Highlights from this chapter include:

- Interpersonal communication challenges
- The interpersonal context for adolescents with ASD
- Social skills in the community, workplace and school
- Tips for improving communication and social skills
- Dating and sexual relationships
- Community engagement
- Leisure and recreation

The Significance of Social Skills in ASD

Social competency is an important area to focus on when preparing your adolescent for adulthood. Many individuals with ASD struggle to understand and use the appropriate social skills for a specific situation. Once students leave high school, situations requiring social competence tend to far outnumber those requiring academic skill. Inadequate social skills may impact success in areas of employment, relationships and integration into the community. Core social competencies range from basic social skills to the more

complex aspects of reading subtle social cues and accurately interpreting the perspective or point of view of another person. Non-verbal body language, understanding other people's feelings and appreciating the unique social culture of a workplace or other settings is also important.

Interpersonal Communication Challenges

Individuals on the autism spectrum often find it difficult to communicate their wants, needs, likes and dislikes. For example, a student with ASD who receives good grades in a computer science class, but who does not know how to make a phone call or engage in a social conversation in the school cafeteria, is someone who might benefit from social skills training. As such, instruction in the following communication skill sets may be appropriate as a function of individual interest and/or ability:

- * Expressing preferences or likes
- * Eye contact during regular interaction
- * Listening skills
- * Ordering lunch
- * Proper use of voice volume, tone and tempo
- * Understanding who is the appropriate person to ask for help
- * When, and with whom, to start a conversation
- * How to switch topics smoothly or end a conversation

Social instruction may need to address conversational skills like how to initiate, sustain and end a conversation. Teenagers with ASD may make seemingly irrelevant comments or focus too much on their special interests. Basic conversational exchanges and the slang or "cool" vocabulary of high school culture may also need to be learned.

Many social behaviours are challenging for individuals with ASD. Therefore, some of the core areas of social competence that may be of concern include:

- * General manners, including responding to greetings and not interrupting others
- * Table manners, particularly if one wants to be socially included with colleagues during meals
- * Awareness of others' personal space across all work, school or public environments
- * Understanding private behaviour as being different from public behaviour
- * Recognizing when assistance is needed; how and who to ask for help
- * Tolerance of unusual sounds, actions, behaviour of others and changes in schedule of activities
- * Social rules regarding the appropriate touching of others
- * What to do on a break at work
- * What to talk about and what not to talk about with others
- * Understanding how to dress for work and the importance of personal hygiene

The Interpersonal Context for Adolescents with ASD

During the teenage years social issues are more prominent in school culture. Adolescents become more aware of other people and the nature of their relationships with them. While most teenagers are concerned with acne, popularity, grades, sports and going on dates, adolescents with ASD may become painfully aware that they are different from their peers. For some adolescents, this awareness may encourage them to learn new behaviours and try to improve their social skills. For others, bullying, hurt feelings and challenges connecting with others at school may lead to feelings of depression, anxiety or loneliness.

Some adolescents with ASD may express the tension and confusion that can occur during adolescence through anger or aggressive behaviour. Adolescents with ASD will also need support to help them understand the physical changes in their bodies and the sexual maturation they experience during adolescence. If your adolescent seems to be having more difficulty coping with the changes that occur in puberty than you would expect, talk with his/her doctor about possible co-occurring mental disorders and ask what you can do. Behavioural therapies and medications are often helpful.

Social isolation has a profound effect on people with autism. It can often result in a lack of peer relationships outside of the school and family environment. Some individuals with autism may never develop meaningful peer relationships. Other individuals make an effort to interact, but because of the degree of their impairment, they are unable to form friendship connections and can become socially isolated. Often, social isolation begins in the pre-teen years. This behaviour is dependent on the degree of social and communication challenges of the individual. As individuals mature into adulthood, there are very few programs that focus on social difficulties. There are some programs that appear to be promising for individuals with ASD (e.g., PEERS®) that can help improve the likelihood of success in the realm of friends and social relationships.

Social Skills in the Community, Workplace and Training/College

Social skills encompass the ability to make friends, interact appropriately with people, recognize social subtleties of humour and sarcasm, and set and respect the personal boundaries of other people. Some of the most important communication and social skills needed for success in the general community, at work and in post-secondary school include the following:

Using Social Amenities – Students with autism sometimes do not use social amenities. Phrases such as “please,” “thank you,” and “you’re welcome” are simple, short and can be easily taught. Although many individuals might know to use these phrases with family members, it might be necessary to teach them to use these phrases at school, at work, in stores, restaurants and other places in the community.

Greetings –The way in which individuals with ASD greet or acknowledge other students and co-workers can also be of concern. Some young adults with autism simply fail to say hello to others, whereas others greet the same people over and over again. Teaching the appropriate use of social greetings can be helpful, especially as the young adult strives to fit in at college or the workplace.

Ending Conversations – Some individuals with autism, even if they are intelligent and have good verbal skills, need to learn how to properly end conversations. Individuals with ASD may sometimes walk away from a conversation without properly ending the interaction or before the other person is finished speaking

Waiting in Line and Taking Turns – Waiting in line and taking turns can be challenging for anyone. For some people with ASD, waiting in line can trigger behaviour that is unacceptable in the community, such as cutting in line, pushing, or walking directly up to the counter. Some students with autism may need to be taught how to behave in crowded situations and when waiting in lines.

Accepting Correction – Difficulty accepting correction is not limited to individuals with autism. Many people do not like to receive criticism – even when it is “constructive”. However, individuals with ASD often react more strongly. Social skills training may need to focus on teaching your adolescent exactly what to say and do when given correction so as not to offend the other person.

Accepting Suggestions – Some students with autism have trouble accepting suggestions or appear rigid in their thinking or behaviour. If a teacher or another adult provides a suggestion, this can result in refusal to take the suggestion, and can even serve as a trigger to acting out behaviour. Providing general instruction on the need to accept suggestions, followed by regularly scheduled role-playing and the opportunity to practice accepting suggestions can be effective.

Asking for Help – One of the most important social skills at home, school or work is to ask for help when needed. When faced with a difficult situation individuals with ASD might become upset, stop working or even leave. Students with autism might also be reluctant to reveal that they have a problem and that they need help. In either the work or school

setting, social skills training can be used to teach individuals how to ask for help and who to ask for help. It is also important to provide some context about the issue when describing it to others.

Tips for Improving Communication and Social Skills

These three methods are often used to help improve the communication and social skills of youth with ASD: Reinforcement, visual supports and technology aids.

Reinforcement of Social Skills. Reinforcement can be a very effective way to teach new skills. Provide meaningful reinforcement when your adolescent demonstrates a desired skill. Remember, reinforcement must be specific to the individual and not a generic item or activity. Individuals with ASD may require very unique forms of reinforcement.

Safe Place. It is also helpful to establish a “safe place” where an adolescent can go for help, to calm down or to make an action plan for how to navigate a social situation. This is often a useful strategy when people feel out of control or overly anxious.

Provide Visual Supports. Visual supports promote understanding and expression, as well as assist in learning new tasks and skills. The skills that may be the most difficult for the individual to master include social communication competencies. Strategies and supports that may be considered for a school and transition program include:

- * Written scripts to teach and support social interaction
- * Visual reminders of the rules or social norms in terms of what “to do” and the “hidden curriculum”
- * Use of videos of the person or others performing a task or using desired social skills

Offer Technology Aids

Use email to communicate clearly and concisely with an adolescent who is competent with the technology. This may allow for more time to focus on and better understand the message. Tablets and smart phones provide a quick, portable way to present video modelling, social scripts, reminders and other social and communication supports. There are many helpful Apps available. These Apps vary from visual sequencing tools to calendars and educational games.

Building Positive Social Networks

One way to improve the social life of a teenager with ASD is to broaden the network of people who like and care about them. Many of the people involved in your young adult's support network leading up to graduation will not be there after graduation. Developing comprehensive and effective support networks is, almost by definition, an ongoing process.

Friendships and Relationships

It is important for your adolescent to be taught the difference between a family member, stranger, acquaintance, friend, or boyfriend/girlfriend and what types of interactions are appropriate.

Some suggestions for how to initiate and build friendships and other interpersonal relationships include:

- * Create flash cards with pictures on them and label them friend, family, acquaintance, and others, along with the roles and interactions associated with each.
- * Give scenarios and engage in role-plays about how he/she would interact with the other person. Consider videotaping these role-plays and using them later for video modelling.
- * Develop a list of rules, which may be useful to govern interactions with different types of people.
- * Provide the opportunity to practice using these new discrimination skills in the social environments where they would be of most use (e.g., the shopping mall or at work).
- * Discuss what makes a good friend and what qualities they would like in a friendship.
- * Discuss different types of friends, such as family friends, best-friends or co-workers
- * Brainstorm possible places to meet people who could become friends.
- * Stress that friendships often take time to develop and require multiple meetings with the other person.
- * Does your young adult have any special interests that others may share? If so, can these serve as the basis for a social relationship or friendship?
- * Create scripts of conversation starters or appropriate topics of discussion that could be used.

Dating and Sexual Relationships

As your adolescent matures, it is necessary to educate them about the changes in their body and feelings. Puberty can be a difficult time for most adolescents, and an especially confusing and challenging time for individuals with ASD. One transition task is to decide on the best way to address these physical and emotional changes with your young adult while keeping open and positive methods of communication. This is also an important time to address relationships with members of the opposite sex, and to clarify

appropriate social skills related to both friendships and to dating, while reinforcing some of the differences between the two. As a parent it is important to know what, if any, sexuality education is being provided by the school or any other support organization.

Sample questions to ask your son/daughter include:

- * What kind of dating experience are you looking for?
- * Are you interested romantically in boys or girls – or both?
- * What are your sexual interests and how can we help you to explore these safely?
- * Are you interested in dating someone? If yes, what aspects of dating are you interested in or not interested in?
- * Have you been involved in an intimate relationship or had sex with someone?

Adolescents with ASD are just as curious and interested in romance and sex as their peers, but are less likely to have a partner because they may have fewer social opportunities to connect with other adolescents. Some of the most common challenges are a result of the widespread myth of asexuality and other negative stigma surrounding people with disabilities. Youth with disabilities may have barriers to getting together with friends and participating in after school activities due to of a lack of independent transportation. Physical and sensory challenges, anxiety about body image and low confidence are also factors that may affect an individual's ability to initiate an intimate or sexual relationship.

Community Engagement

As the saying goes, “It takes a village to raise a child”. This is especially true when the focus shifts from the high school years to adult life. You may want to think early on about how to best integrate your son/daughter into the community.

There are many ways in which your adolescent can become engaged in the community:

- * Trips and outings
- * Exercise and sports programs
- * Hobbies, games, arts and crafts
- * Social events
- * Youth groups or religious community activities
- * Special Olympics
- * Leisure and recreational programs (e.g., YMCA or community centres)

Community Engagement Fosters Social Well-Being

Integration into the social community is a key component of happiness and independence in the lives of adults with autism. Interacting with others by participating in sporting events, joining a local club or being a part of a religious community will improve self-esteem and confidence, and provide great enjoyment and pleasure. Developing ties with people in the community can also be an important factor in maintaining safety (i.e., knowing who can help in an emergency).

Barriers to Social Engagement

Families may feel that as children enter adolescence, social differences become more apparent and opportunities for leisure and socialization in the community become more difficult. As your child grows older, you may need to become more creative in your efforts to create opportunities for social interactions. Community agencies and support programs can provide information and community opportunities and, in some cases, offer direct financial support for participation. However, for many adults with autism, using basic public services to engage with the local community can be a challenge. When pursuing mainstream services like health care, employment support and educational program benefits many individuals with ASD struggle to navigate these systems efficiently. For example, many adults with autism are reluctant to use public transportation because they find the task daunting, which then renders them unable to participate fully in the community (see next chapter).

Some tips on how to increase community engagement include:

- * Have a discussion with your young adult about the people they encounter on a daily basis.
- * Talk with your adolescent about the different types of people they know and the appropriate way to act around each type.
- * Ask how well people in the community know your adolescent and what do they know about him or her (e.g., where he/she is most likely to work, shop or recreate).
- * Inquire about service organizations at local high schools or post-secondary schools that coordinate a buddy or mentor program in which same-age peers are paired with individuals with disabilities for social outings and activities.

Leisure and Hobbies

Many adolescents with ASD spend their leisure time engaged in certain areas of interest or specific topics that they really like - math, animals, comic or a specific video or computer game, etc. As part of the transition planning process consider how individual interests might be used to help your son/daughter develop contacts outside of the classroom. Some leisure time interests or hobbies have related organizations or groups that meet socially, such as science fiction clubs, computer technology clubs, chess clubs, military history clubs, and so on. Introduce your young adult to these groups and encourage them to participate. As your young adult gets older, having the ability to meet new people based upon similar interests, and to expand potential social networks is extremely helpful.

High school clubs, sports teams, after school programs and school-sponsored activities are all opportunities for participation in leisure with other same-age people. Intramural sports can also be a good way to make new friends and get exercise as well. Keep in mind that some teams or programs (particularly if they are highly competitive or involve physical contact) may not be possible or a good fit for your adolescent.

Recreation

The physical and emotional benefits of recreation (including the social connections that can accompany recreational activities) can be important for creating a fulfilling and joyful life. Recreation is more than planned programs that happen in a park or the gym. It can be any activity that helps a person explore things of interest to them or it can be an opportunity to simply relax and have fun. Families can help their adolescent find recreational opportunities. Recreation can happen in the home or in a community setting, it can be structured activities or an informal hang out with a friend or neighbour.

Preparation for Leisure and Recreation Activities

Often it can be helpful to prepare your adolescent for participation in these activities with social stories, schedules of what is going to happen, behaviours to expect and so on. Use some of the same strategies that are effective in teaching other skills to your child. Before you register your adolescent for an activity, it is important that you speak with the activity leader. Talk about the positive attributes of your adolescent, as well as some of the challenges he/she may have specific to the activity. Ask if you can bring your adolescent on a trial basis to see if some of these new activities are fun and worth committing to on an ongoing basis.

In some cases, it may be helpful to have an aide (who already knows your son/daughter) go along with you to the first few sessions to ensure that participation in the activity is a success. If your adolescent will be bringing an aide to the activity, it will be important to explain the aide's role as well. It may also be helpful to bring the aide on your trial visit so that you all meet the leaders of the activity, and ensure that everyone is comfortable before participating.

Tips for Recreation Planning

Here are some tips to help guide possible plans for recreational experiences:

- * Highlight your adolescent's strength and interests.
- * Remember that "fun" is a personal experience. Fun for your adolescent may be different than for someone else.
- * Make friendships a priority as adolescents benefit from sharing fun activities with their peers.
- * Encourage your adolescent to try out new and different activities.
- * Explore organizations that offer recreational activities that may be a good fit for your adolescent. Inform the staff about any needs for physical adaptations or other accommodations your adolescent might need to participate more confidently in recreation activities.
- * Encourage your son/daughter to try new things as recreation options. Helping them try new experiences can support the use of new skills or being in unfamiliar social situations.
- * Ask other parents about successful recreational experiences and collaborate on creating new ones.
- * Surf the Internet for groups dedicated to common interests and recreational group outings. Remember to review Internet safety with your adolescent and have an open dialogue about meeting new people safely when using the computer.
- * Identify the activity calendars of local agencies that serve persons with similar disabilities for local events (e.g., Special Olympics, etc.).
- * Let your son/daughter take the lead as a teacher with something they are good at doing. If they excel at video games or trivia, ask them to teach you how to do something new.

Recreation Opportunities at Day Rehabilitation Programs

Some young adults with ASD attend structured programs during the day where they work on a variety of skills and enjoy recreational and social time with others. These programs usually take place at community agencies, have employed staff members, and are funded by government or not-for-profit agencies. Goals may focus on improving communication skills, personal care, leisure and motor skills, as well as socialization and immersion in the community. Activities may include: exercise, community experiences, volunteer opportunities, art and music therapy, food preparation, and personal care needs.

Goals to Work On (Communication and Social Relationships)

1. _____
2. _____
3. _____

Launch Domain #4:

Independent Living Skills And Self-Advocacy

This part of the Guide focuses on the practical aspects of transitions to independent living, such as the development of skills for managing daily life, using local transportation, managing finances, obtaining housing and personal safety. The goal of independent living is to learn how to take care of oneself and to develop a strong sense of self-advocacy and self-determination. Highlights of this chapter include:

- Daily living skills
- Differences in skill level
- Transportation and travel
- Obtaining housing
- Personal safety
- Self determination

Daily Living Skills

Assessing where your adolescent is developmentally and functionally with respect to their independent living skills is a significant part of the transition process. It is important to develop skills early and to practice them often so that your son/daughter will be better able to do required self-care tasks later in adulthood. This means looking at knowledge, understanding, and ability to perform certain tasks, usually relating to self-care, problem-solving, decision-making, social awareness, and other areas. These assessments will help determine what assistance or training the individual may need to live as independently as possible. *The following are a few key areas you may want to consider when assessing independent living skills:*

Daily Living Skills. Daily living skills are sometimes referred to as “Activities of Daily Living” or “ADL’s”. These skills include, hygiene, toileting, bathing, dressing, cooking, cleaning, laundry, shopping, using the telephone and taking medications.

Time Management Skills. Time management refers to the ability to understand time, punctuality, task prioritization, daily schedules, short-term versus long-term concepts, and deadlines.

Money Management Skills. Managing money includes the ability to understand the value of money, spend within means, pay bills, purchase items and receive change, use banking systems (including credit and debit cards), and awareness of fraud or scams.

Organizational Skills. Organizational or “executive functioning skills” are critical for success in post-secondary education and in the workplace. Organizing assignments, managing time, setting priorities, and breaking projects down into steps are all key skills that need to be learned as early as possible.

Work Skills. Work skills overlap with many of the domains described in this section. They also include mastering skills related to job searching, interviewing, communicating, initiative-seeking, and exhibiting professional courtesy and interpersonal skills.

Health Management Skills. Your adolescent also needs to be involved in and manage their own health care to the greatest extent possible. This includes scheduling doctor’s appointments, understanding their medical and mental health conditions, recognizing medical symptoms that need attention, awareness of mental health needs, medication management and adherence, healthy eating and exercising, and knowledge about tobacco, drugs, alcohol, and sexual health.

Social Skills. This includes your adolescent’s ability to make friends, communicate with people, recognize non-verbal cues, set and respect personal boundaries, and safety around sexuality as well as drugs and alcohol.

Community Navigation Skills. This refers to knowledge and comfort around interaction in the community, interacting with others, asking for help, personal safety and obeying the law.

Differences in Initial Skill Level

Adolescents and young adults with ASD vary tremendously in their level of maturity and capabilities for managing the needs of daily life. Improving basic life skills is most effective when approaching the problem from a realistic vantage point that recognizes the starting point of the individual. Therefore, it may be useful to consider the four potential approaches outlined below:

1. If you can teach the skill, teach it. For example, if you can teach an adolescent to purchase something at a store and use money, teach them to do it.
2. If you can't teach the skill, adapt it. If the adolescent cannot count change, but can use a debit card appropriately, have them use a debit card.
3. If you can't adapt the skill, find some way around it. If an adolescent cannot manage use of a debit card, can they use a gift certificate or pre-paid card at a specific store?
4. If you can't find some way around it, teach others how to deal with it. If an adolescent cannot master how to hand money to the cashier or wait for change, go to the local store that he/she will be using and get to know the manager and employees. Explain the limitations your adolescent has and suggest ways that they can help or prompt the behaviour that is required.

Enhancing Development of Independent Living Skills in the Real World

There are many creative ways to teach skills and to help your adolescent integrate into the community and promote independence. Once these different skills have been assessed, it can be useful to brainstorm ways of addressing and teaching needed skills or finding viable strategies to work around them. It is also important to train and practice these skills in real world settings where they occur. Here are some suggestions:

- * People learn things best when they use the real item. For example, using real money when learning to make purchases.
- * People learn things best when they do them at the time they are usually done – like brushing teeth after a meal or before going to bed.
- * People learn best from other people who are involved in the situation – like co-workers who have the same job tasks.
- * People learn best when the things that they learn are useful – like using the telephone, taking the bus or making a meal.

Transportation and Travel for Independent Living

Another transition to prepare for is the area of transportation and travel. As a parent, you or other family members likely do most of the driving to get your adolescent around town. Understanding and using local transportation options safely is an important next step for adolescents to gain more independence, to get to school or work, and to simply

gain greater access to the community. Some young adults with ASD can also learn to drive a car. Travel over longer distances will require learning how to travel safely on airplanes, trains, or travel coaches (buses). This may also include the need to teach the skills required for passing through security check-points, customs and immigration. For this purpose it can be useful to have a letter from a physician or personal identity card that describes your adolescent's diagnosis of ASD, including what behaviours might be displayed and strategies for effectively managing certain behaviours.

Local Public Transportation

Even though many school systems and metropolitan areas have some form of transportation services dedicated to supporting those with a disability, it is still important for young adults with ASD to learn how to use other forms of local transportation. Common forms of getting around the neighbourhood and local area include the use of city buses, commuter trains and taxi cabs. It is important to review the train or bus schedules to help your child determine the appropriate time and route to get him to the destination. Review maps of the bus routes together, as well as where your home is located in relation to the destination. If necessary, use a trainer or aide in the actual setting. Practice using the bus with your son/daughter or have a peer mentor or community access worker travel along until he/she is confident and capable of travelling alone. When using public transportation, acquiring the skills for proper social conduct and safe use of money to pay the fare is also needed.

Driving

In many parts of Alberta, it is possible to get driving lessons from a driving school or a rehabilitation centre that caters to the needs of individuals with disabilities. Such training should highlight safety rules, such as not talking on the phone when driving, changing the radio station, or engaging in other distracting behaviours. Another tip is to keep important directions to home and other places easily accessible in a file in the glove compartment. As with all teenagers, parent supervision is very important while learning how to drive.

Long-Distance Travel

Travel training for individuals with ASD should also be part of the transition period. Airplanes, motor coaches/buses, and trains are common options for personal and family travel. Travel training is a proactive tool that will play a positive role in establishing more independence for your adolescent. There are many skills that individuals will need to possess in order to travel safely including the ability to read maps or ask for directions, paying fares, remaining in your designated seat for long periods of time. A travel coach will help your adolescent by addressing his/her needs at whatever pace is required.

Security Issues with Travel

Parents may want to consider taking some extra measures to make passing through a security checkpoint at an airport or border crossing easier. As daunting as a security checkpoint is for some children and adults with ASD, you must consider the point-of-view of the security professional. The behaviour or characteristics of your child may make security professionals anxious. Consider the reliance on visual cues typical of a person with autism, such as repeating a phrase observed on a nearby poster. At a security checkpoint that behaviour might include words featured in the laws or that warn specifically against the use of certain words – such as “bomb threat” or “hijacking.” Someone who repeats these words would quickly come under suspicion at a security checkpoint. People who repeat a question, run away from a metal detector, or become over-anxious at attempts to touch them would also merit extra scrutiny. Left unexplained, these kinds of behaviours and characteristics of a person with autism may delay their trip and cause unnecessary anxiety. Even worse, these kinds of encounters can quickly escalate into misinterpretations, verbal and physical confrontations, and possible containment and restraint from law enforcement.

* Having a letter from your medical doctor, wearing a medical identification bracelet or carrying a disability identification card could prevent a security or police officer from misinterpreting behaviours

Plan Ahead for Air Travel

In light of these potential risks, it is advisable to make travel plans well in advance of the intended trip. Call the airline and any associated security programs and ask what you can do to help the check-in and security screening experience go more smoothly for the individual with ASD and the security professionals they will interact with. If the trip has to be made without advance planning, try to arrive extra early, bring printed information about ASD and explain to the gate agent what your needs are. Some air carriers also offer special assistance services for inexperienced, young or disabled travellers, so it can help to ask if such programs are available.

Make behavioural expectations for air travel clear by employing tools such as social stories, apps and videos to familiarize your adolescent with travel etiquette and rules. For example, placing baggage under the seat, turning off electronic devices, waiting your turn to get off the plane, keeping your voice at a conversational level and deciding when it is appropriate to ask the flight attendant for help.

Obtaining Housing

Thinking about where your young adult with ASD will live after high school can be a stressful issue that is full of uncertainty. Some of the core questions include:

- * What are the options for housing?
- * What if he/she cannot live alone because of not being able to take care of him or herself?
- * Will my child be well cared for and happy?
- * Will my child have access to friends and community involvement?
- * Who will pay for it?
- * What funding options are available in my province (i.e., individual PDD funding or other low income support programs)?
- * How will my child get around? What transportation options are available?

Planning for this process and deciding where to live is very important and requires a great deal of research, networking and preparation. If your son/daughter has more cognitive and intellectual disabilities, they may qualify for services through the government as an adult. However, unlike educational services, these services depend on the qualifying criteria and are not funded as social entitlements.

Types of Living Arrangements for Adults with ASD

Multiple housing options exist and it's important to remember that each individual will have different needs and choices. Helping your son/daughter choose the right place to live will largely depend on what is available in your community that is a match with your adolescent's daily life skills and overall level of functioning. Below are some examples of living arrangements you may want to consider.

Independent Living. Many young adults with ASD are able to live in their own home or apartment with little or no formal supports. Others can live in their own home or apartment if they have help dealing with major issues, such as managing personal finances, obtaining necessary health care, and interacting with government or social service agencies. This support can be provided by a supportive roommate, family

members, professional agencies, or other types of providers - depending on the level of support required. Individuals who qualify for government supports may apply for funding to pay for a roommate or agency supports.

Living at Home. Many young adults with ASD continue to live at home with their parents and family after high school. Government funds are available for families who choose to have their adult child with ASD live at home. Information about these programs and others is available in the Resources section of this Guide.

Living With Another Family. Often referred to as ‘home sharing’, some families open their homes to provide long-term care to adults with disabilities who are not related to them. Living with another family is also called a ‘supportive living arrangement’ where one of the parents of the family takes on the role of ‘supportive living roommate’. Responsibilities are determined by the level of support the individual with ASD requires and can include transitional goals such as supporting development of independence skills required for a future goal to move to a supportive living roommate situation in their own apartment or own home. Funding for a roommate salary can be negotiated through government and community supports if the individual qualifies.

Supervised Group Living. People with ASD can also live in group homes or apartments staffed by professionals who help with basic needs including: meal preparation, housekeeping, and personal care. People who are more independent may be able to live in a home or apartment where the staff only needs to visit a few times a week. In such arrangements, the person can generally prepare their own meals, go to work, and conduct other daily activities on their own.

Day Treatment and Rehabilitation Programs. Day treatment programs are for individuals that may need the most intensive level of supervision and support. Day treatment programs combine therapeutic treatment with daily life skills. This type of program is administered at a program site rather than in the community. Day programs provide structured activities and specialized supports that will allow individuals with autism to participate in non-employment related activities on site and in the community.

Long-term Care Facilities. This alternative is available for those adults with ASD who need intensive, constant supervision. This living arrangement is a full-time residential care facility for the person and others with similar disabilities and special care needs.

The Search for Appropriate Housing: A Four-Step Approach

The process of finding an appropriate place to live takes some time and involves a number of steps. Here are four helpful steps to follow:

Step 1 – Envision the ideal living setting. All parents want their children to be safe and happy as adults. It can be helpful for you to try and envision what environment would be best when you begin to think about adult living situations for your son or daughter. Where would your young adult thrive? Does he/she prefer the country or city? What are the options for transportation? How important is it to live close by you or other family members?

Step 2 – Identify your young adult's specific needs and abilities. Determine what supports will be needed to make the living situation workable. Key among the skills young adults will need to live independently is the ability to manage finances, shop, cook, clean and manage personal hygiene.

Step 3 – Determine your realistic housing options. Once you and your young adult have identified an ideal living situation, the next step is to determine whether such a setting already exists or whether the family will have to create the setting. Do your homework to determine what's out there. You can also try to create a more unique option for housing, such as co-investing in a group home with other parents and adolescents or self-funding other appropriate living situations.

Step 4 – Select where to live. Once you've imagined the ideal setting, taken into account your young adult's unique needs and explored the housing options that meet those criteria – the final step is to select the place where to live. For each of the available choices, you and your young adult should then take a tour of each place in order to narrow down the options. It can be useful to make a visit unexpectedly to see what the accommodation is like under normal conditions when a special visit is not planned.

Personal Safety

Safety is a very important topic to consider for housing and independent living. Does your child lack certain skills that can help him determine if a situation is safe? Discuss how to recognize and avoid potentially dangerous situations that may occur as your child matures, including advances from strangers. For learners whose verbal comprehension may be limited, discrimination training may be needed to help distinguish strangers from friends and good-touch versus bad-touch.

Some with ASD may be prone to wandering off or leaving a safe environment or may not be able to recognize danger. Wandering, elopement, “running” or fleeing behaviours not only present unique safety risks, but also create extraordinary worry and stress among parents and caregivers. Sadly, drowning fatalities following wandering incidents remain a leading cause of death among those with ASD.

Statistics also indicate that people with cognitive disabilities are at high-risk of being the victims of sexual and physical abuse. It is critical to keep this in mind when assessing safety skills.

Safety is increased when your adolescent has knowledge of basic personal information (name, address, calling 911), household safety issues (fire, gas smells, locks, emergency numbers), medical safety concerns (doctors’ numbers, when to seek medical attention), general physical safety (traffic rules, seat-belts, avoiding strangers) and sexual safety (awareness of risk for sexual and physical abuse).

Individuals with ASD and other developmental disorders can have difficulty if they come into contact with police as their responses to encounters with law enforcement officials may not always be socially appropriate. Police officers and first responders may unexpectedly encounter or be asked to find and/or intervene with a person with ASD. Typical problems include running away, impulsive behaviour or failure to respond appropriately to questions. The problem is that such behaviour may be misunderstood by law enforcement professionals and can lead to serious consequences and even arrests. For this reason it can be helpful to have an Identity Card or Medical Alert Card that indicates a diagnosis of ASD and some of the expected behaviours as well as strategies for effectively managing these behaviours so as to avoid further problems.

Additional Safety Skills:

- * Recognize and respond to law enforcement officers, their uniforms, badges and vehicles.
- * Stay with — do not run from — police officers or other uniformed first responders
- * Keep an appropriate distance when interacting with a law enforcement officer
- * Avoid making sudden movements or putting hands into pockets
- * Carry and safely show an ID card
- * Disclose your autism, carry and safely show an autism information card
- * Recognize inappropriate touching or sexual advances directed at them
- * Effectively report bullying or other incidents
- * Tell someone you need help, or use the phone to request it
- * Always let someone know your schedule (i.e., where you are going, your route and timing)
- * Carry a cell phone (possibly with apps for tracking the phone) and keep it turned on

Self-Advocacy

Adolescents with ASD need training and opportunities to learn self-advocacy skills and how to participate meaningfully in key decisions affecting their life. Making choices and decisions is also part of self-determination and is an important life-long skill. For this reason, whenever possible, transition planning should include an opportunity for the youth to present his/her own vision for life as an adult. For the transition from adolescence to young adulthood to be successful, your adolescent must be able to advocate for himself and take control over appropriate aspects of life. Indeed, even though parents contribute so much to launch their son or daughter into adulthood, their child's future is their own.

Self-advocacy should be taught throughout a person's lifetime. It can start in small ways by teaching an individual to make choices. Gradually, more advanced skills such as those involving negotiations and disclosure should be added, if appropriate. Learning to ask for help is another step in developing self-advocacy skills. In order to do this, the individual must be able to identify that there is an obstacle or difficulty, and then seek out assistance to have the issue resolved. The goal of self-advocacy is to make sure that young adults have as much input as they are capable of providing regarding their thoughts and dreams for the future. It is important to respect your adolescent's wishes and needs, and encourage others to do so as well.

Disclosure of Having a Disability

Part of self-advocacy often involves the ability to disclose to others that one has ASD. An adolescent with ASD needs to be specifically told about their diagnosis. Many families have shared with their child that ASD may have provided him or her with strengths such as a very good memory, tremendous knowledge about a specific topic, or strong skills in a particular subject at school. It is important to let the individual know that ASD may also makes some things more challenging and then list some of the things that may be difficult for the individual.

Each individual will react differently to learning about the diagnosis of ASD. It may be helpful to come back to the subject from time to time so that the adolescent can process the information as he/she matures physically and cognitively. It may also be helpful for your adolescent to join a support group or a social skills group for those with similar abilities.

Teaching Self-Advocacy Skills:

Teaching self-advocacy skills is an on-going process. It will take time for your adolescent to build these skills. There are many opportunities for teaching self-advocacy skills throughout the course of the day. To foster your adolescent's independence, try to involve him/her in decision-making and provide opportunities for them to make choices everyday. Choices for meals, leisure activities and even which chores to do around the house. Other choices may include:

- * Timing of events – Choosing when to get up, when to go to bed at night, when to get a haircut or when to eat dinner.
- * Personal choices – Choosing what clothes to wear, what shampoo to buy or which cereal to eat.
- * Methods of training – Choosing where learning will occur or who will provide the support. For example, doing one's daily school work at home or at the library.

By encouraging your adolescent to make his/her own choices, you are empowering them to become more of a self-advocate and to be more independent.

Self-Determination

Ultimately, to be successful in higher education or the workplace, youth must develop skills that allow them to become as independent as possible. Skills such as self-knowledge, goal setting, decision-making, problem solving, and self-advocacy are crucial for young people with disabilities. These skills are all considered aspects of self-determination. Youth who leave high school with self-determination skills have a greater chance of achieving positive life outcomes than those who do not. Self-determined youth will also be able to exert greater control in the selection and use of adult services and supports in their post-secondary education and employment goals.

Self-determination can be defined as knowing oneself, one's goals and how to achieve those goals. It includes knowing strengths and acknowledging areas of challenge. In environments such as college or the workplace, they also have to know how to ask for accommodations or supports when needed. Becoming self-determined is a process of developing and implementing a realistic plan for one's life. It requires an awareness of one's strengths and challenges along with the knowledge and skills needed for adult life.

This process takes time, and most students need teachers, family members and others to provide them with opportunities to become self-determined. Parents play a critical role in the development of self-determination by acting as models of self-determined behaviour and by interacting with their children in ways that promote self-determination. Home environments can provide safe opportunities for exploration, choice, taking

risks and exercising control. Examples of activities that foster self-determination include promoting choice-making, self-directed school projects, scheduling personal appointments (e.g., medical, hair cuts, etc.), budgeting allowances and making small purchases. These are all situations where students can plan, make choices and decisions and that allow them to use skills that will be necessary for future independent living.

As a parent, you can help your adolescent develop self-determination skills by creating a supportive environment at home. This context should allow youth to take risks, test their abilities and limitations, develop their problem solving skills, and practice positive work habits and behaviours. This means that they start to take on more responsibility for their education, employment, health care, and living arrangements. An understanding of oneself, including the limits and strengths of one's health and disability, is key to becoming an effective self-advocate and essential to post-secondary education and employment success.

Goals to Work On (Independent Living Skills and Self-Advocacy)

1. _____
2. _____
3. _____

Launch Domain #5:

Legal And Financial Issues

This part of the Guide provides an overview of legal and financial arrangements that support independent living for ASD youth. It includes the legal matters of guardianship, trusteeship and the financial matters of wills, trusts, financial planning and letters of intent. Highlights of this chapter include:

- Legal matters
- Financial matters Making a life plan

Legal Matters

The transition to adulthood also entails taking care of important legal matters, most of which must be done prior to your child turning 18 years of age. All parents should understand the differences between a Guardian and a Trustee.

The Legal Milestone of Age 18

Finding the balance between encouraging independence and ensuring that your young adult is safe can be challenging. However, after the child's 18th birthday parents are no longer considered to be legal guardians. This is true even if he/she has a disability. According to the law, all persons 18 years and older are presumed competent, that is, able to make decisions about health care, finances and other important areas of life. This means your adolescent is able to give "informed consent" and to make their own decisions in all matters. If you feel your adolescent is unable to give informed consent or make important decisions on their own, you may need to consider the option of becoming your child's legal guardian and or/trustee.

Legal Supports for ASD Adults

Traditionally, the legal system in Alberta has emphasized two forms of support: Guardianship and Trusteeship. The distinction between these two terms is that guardianship pertains to personal decision-making, whereas trusteeship pertains to financial decision-making. More recently, supported decision-making and co-decision-making are additional legal options that are not as restrictive as full guardianship.

Examples of personal decisions made by a Guardian:

- * Health care for the adult
- * Where the adult lives
- * With whom the adult associates
- * Social activities
- * Educational and vocational training
- * Employment
- * Non-financial legal proceedings

Examples of financial decisions made by a Trustee:

- * Managing income (e.g., AISH – Assured Income for the Severely Handicapped, employment income)
- * Managing other assets (e.g., real property, RDSP – Registered Disability Savings Plan)
- * Budgeting money
- * Managing expenses
- * Maintaining proper banking and financial accounts
- * Investing money in accordance with Court-mandated standards

Considerations with Guardianship

Typically one or both parents seek to be appointed by the Alberta Court as the guardian(s). Consideration should be given to additional or alternate persons (siblings, family or close friends) who might be willing to assume the role of guardian upon the death or incapacity of the parent(s). Choosing support for your adult child can be a difficult and complex decision. Before you make this decision you should:

- * Carefully consider your child's specific strengths, vulnerabilities, needs and best interests.
- * Learn about the different levels of legally recognized decision making support in Alberta such as; Supported Decision Making Authorizations, for those persons who need minimal assistance; Co-Decision Making Orders for those requiring a greater degree of support and Guardianship Orders for those needing the greatest level of support. In order to be the Co-Decision Maker or Guardian for the young adult, an application must first be made to the Alberta Court
- * Speak with professionals who have worked with and who know your adolescent- such as teachers, school administrators and therapists or other professionals – about what kinds of personal decisions are most in need of support and which are appropriate to leave to the youth.
- * Speak with health professionals to determine whether a Capacity Assessment Report is required. This report is a prerequisite to obtaining a Co-Decision Making Order or Guardianship Order from the Alberta Court. A qualified professional, such as a doctor or psychologist, must complete it.
- * Ask for advice from legal professionals who specialize in the field of guardianship and disability.

Financial Matters

Preparing for the future means establishing the legal protections to ensure your wishes are specifically carried out in the best interests of your young adult with ASD. Will and Estate Planning is a critical part of addressing the future. Find a lawyer who specializes in special needs and/or disabilities to help you create the legal estate documents and provide you with advice on setting up trusts tailored to your family. A good lawyer will use appropriate language and methods to provide for your young adult in the future.

Wills

One of the most difficult questions for a parent of a child with a disability is, “What will happen to our family member with a disability when we die or are no longer able to care for them?” While it may be difficult to think about a future when you are not able to care for your young adult with ASD, it is important to begin taking the necessary steps to secure the accommodations and services he/she will need after your death.

A proper Will provides a roadmap for loved ones on how you would like things to be managed after your death. Creating a Will allows you to have a voice in these important decisions. It provides specific, detailed plans for your estate, how your estate will be

distributed after you die, and the care of your young adult. If you do not have a Will, the law imposes a formula for the distribution of your estate. This formula does not take into consideration the special financial needs of your child. Therefore, a claim for a greater share of your estate, brought on behalf of your disabled child may need to be made. Claims against an estate are stressful on families. They are time-consuming, costly and erode family resources that otherwise, with proper planning, could have been used for your child.

It is essential to prepare your Will and estate to maximize the benefits and protections for your young adult with ASD, ensuring financial stability and continued care.

Begin early by identifying key people who can assist in the process of creating a Will. This should include, when possible, your family, your young adult with autism, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, and anyone involved in providing services to your young adult.

Many parents create a trust for their disabled child through their Wills. The purpose of a trust is to ensure that the child's inheritance is carefully managed and protected after the parent dies. The parent may appoint another family member, trusted friend or a trust company to be the "trustee." The trustee's duty is to invest the trust property prudently on behalf of the child and to use the trust funds, when needed, to pay for the child's on-going care.

When planning your estate, consideration should be given to preserving, as much as possible, government subsidies to which the young adult may be entitled. Some subsidies, such as Assured Income for the Severely Handicapped (AISH), take into account the amount of income and assets as well as the kind of assets, owned by or held for the young adult. The level of funding and supports for which the young adult qualifies may then be affected. For this reason, consideration should be given to creating a Registered Disability Savings Plan (RDSP) for your child. Currently, contributions to an RDSP do not reduce or remove a disabled person's entitlement to provincial subsidies.

Financial Planning

Families who have a child or other dependents with special needs, no matter what age or disability, have many serious questions about how best to financially provide for their future well-being and quality of life. The expenses associated with having a special needs child can be substantial and last for decades. It can be hard to find the financial means to cover your child's immediate needs, let alone save for the future. You can begin by creating a detailed budget of expenses that includes everything from housing to personal needs, both currently and in the future. This will give you an idea of how much money will

be needed to care for your young adult. An important task is to determine how to provide for future care and services for your child after you are gone. Consider the financial resources that will be necessary to support your adult child after your death.

You must begin thinking now about how to cover the costs and/or fund your child's future. There are a number of different resources to consider, including stocks, mutual funds, retirement accounts, real estate, home equity, life insurance, and others. Don't forget to include the government benefits that your child may receive. A financial planner can be a very useful person to guide you through this process, especially one who specializes in advising people with special needs. Your financial planner can help you estimate current expenses versus what's needed as savings toward the future and advise you accordingly. They can also provide guidance around savings, investments and life insurance policies, which will accrue over time.

RDSP's (Registered Disability Savings Plans) are a new vehicle to help you plan for your child's financial needs as they reach their more senior years. This is a federal program, which provides grants to the RDSP account based on your contributions.

Many children with ASD have one or more siblings. Often times, your child's siblings will assume some of the responsibility for the care and decision-making for your special needs child after the parents are gone. This requires open, frequent, and anticipatory discussions about the future with everyone involved.

Making a Life Plan

A life plan is a document outlining what the family envisions or wants for the future of their loved ones. This plan is often developed as a "letter of intent" that is written by the parent or caregiver to provide critical information for supporting your young adult with ASD. This letter can include medical and treatment history, current ability levels, and your hopes and goals for the future.

The letter of intent is not a formal legal document, but it provides important context to guide the future care of your child. Practically, it provides detailed information on medical and behavioural history, effective interventions and supports, your young adult's strengths and challenges, and specific care instructions. Some families even videotape daily tasks to illustrate key instructions. A detailed letter of intent will help provide excellent insights for future caregivers and a smooth transition. Start your letter of intent now, and revise and update it, as needed, to ensure that it remains an appropriate resource for your young adult with ASD.

Some topics this letter could cover include:

- * Preferences for daily bathing and dressing, including the type and level of assistance that may be provided and by whom
- * Preferences with regard to music, movies, and related leisure activities
- * Dietary needs and food preferences
- * Environmental preferences (e.g., does not like fluorescent lighting or having the dishwasher on)
- * Personal or idiosyncratic preferences (e.g., prefers a specific coffee mug)
- * Medication guidance
- * Lifestyle options that will ensure quality, dignity, and security throughout adult life
- * Your child's dreams and aspirations

Goals to Work On (Legal and Financial Issues)

1. _____
2. _____
3. _____

Self-Care For Caregivers

Caring for a family member with ASD presents its own challenges and rewards. Parents and caregivers of children with ASD have higher levels of stress and depression compared to parents of neurotypical children. Higher stress levels affect caregiver functioning, which may lead to negative impacts on physical and mental health. Consequently, it is important for parents and caregivers to seek support to maintain their strength and capacity for caring for their ASD family member. Only when we help ourselves first, can we effectively help others.

Caring for and taking the time for yourself is one of the most important (but often the most forgotten) things you can do as a caregiver. Many times personal beliefs and attitudes stand in the way of self-care. For many people, not taking care of yourself is a lifelong pattern, as taking care of others is an easier option.

Remember, it is not selfish to focus on your needs when you are a caregiver- it is an important part of the job. Community organizations, support groups, counselling, and respite care are some of the many options for parents and caregivers to pursue when seeking self-care.

Conclusion

Experts on human development consider adolescence a very important time. It is a “launching period” when parents help youth develop the skills they will need as adults. This “launching” process does not end because a student graduates from high school, reaches the legal age of majority (18) or enrolls in a college or other training program. New and important parenting issues will arise as young adults continue to grow and develop.

Young adults with ASD continue to experience social challenges on a daily basis even after they turn 18. They encounter situations for which they are not prepared or that they do not understand. Subsequently they are put at a social disadvantage. The role of the parent becomes vital in assisting the young person in the transition from childhood to adulthood. Transition planning is about what is possible. It involves having high expectations, taking some risks, and significant effort on the part of the young adult, the family, teachers, school administrators, community members, adult service providers and many others. Good transition planning takes cooperation and time but the outcome is well worth the effort.

Many parents have devoted themselves to learning as much as they can about ASD and have spent countless hours advocating for their children to ensure they receive the maximum services available. But sometimes when you are working on pursuing what is best for your child, you may forget about your own needs. It is important to recognize that you need time to eat, relax, sleep and care for yourself. Make sure the time you devote to your children does not consume your entire life. Take time for yourself. Spend time with your spouse/partner and your friends. It may help to make a social appointment you can't cancel, go to the library once a week, or exercise on a regular basis. Downtime for you is an investment not only in your future productivity and quality of life, but in your family's too. Ultimately, it will benefit your whole family and enable you to better care for your adolescent.

Lastly, remember that you are not alone in this journey. There are many families that have been where you are now and have successfully transitioned their child into adulthood and there are many people and resources available to help you along the way.

Transition Planning Timeline

This part of the Guide offers a detailed tool for tracking a variety of tasks typically required for a successful transition from adolescence to adulthood. For each task that has been addressed, simply check it off and enter the date (month and year) that it was completed. These tasks are organized into the following four age-related stages:

- Stage 1 – Age 13 to 14 - Junior High School Years
- Stage 2 – Age 15 to 16 - Early High School Years
- Stage 3 – Age 17 to 18 - Later High School Years
- Stage 4 – Age 18 to 21 - After High School Years

STAGE 1

Age 13 to 14 - Junior High School Years

Transition Tasks	Completed Date (MM/YY)
Continue regular visits and preventive care for medical health with your family doctor (annual check-up at a minimum).	<input type="checkbox"/>
Continue dental health check-up (check-ups every 6 months are recommended).	<input type="checkbox"/>
Begin or continue conversations and education about physical changes during puberty and answer any questions your child may about sexual behaviour.	<input type="checkbox"/>
Encourage participation in social, sports or recreational activities through school, faith-based groups or community sources.	<input type="checkbox"/>
Seek training and practical support for enhancing communication and social skills.	<input type="checkbox"/>
Discuss transition to adulthood with the youth and other family members during initial assessment or re-assessment of Family Support for Children with Disabilities (FSCD) services as they relate to funding and program support.	<input type="checkbox"/>
Attend a transition seminar or workshop for families.	<input type="checkbox"/>
Research/learn about the Registered Disability Savings Plan (RDSP) in preparation for setting one up when your child is of age.	<input type="checkbox"/>

Transition Tasks

Completed Date (MM/YY)

Introduce the concept of creating a vision for future independence and begin to explore what your child’s future may look like, involving him/her in the process to the greatest extent possible.	<input type="radio"/>
Review requirements (if applicable) regarding eligibility for Persons with Developmental Disabilities (PDD) program.	<input type="radio"/>
If your child meets the eligibility criteria for PDD, ensure all assessments are completed, up-to-date and on file.	<input type="radio"/>
Review requirements regarding eligibility for Assured Income for the Severely Handicapped (AISH) program if applicable.	<input type="radio"/>
If eligibility criteria for AISH are met, ensure all assessments are completed properly and on file.	<input type="radio"/>
If assessments required for PDD/AISH are not available, discuss options for how to have them completed.	<input type="radio"/>
Discuss adult support options available other than PDD.	<input type="radio"/>
Discuss interest in further education options for after high school.	<input type="radio"/>
Discuss interest in kinds of employment options for after high school.	<input type="radio"/>
Discuss interest in volunteering and community engagement options.	<input type="radio"/>
Initial discussion of guardianship issue for after age 18.	<input type="radio"/>

Planning Timeline Summary

Date _____ Age of Child _____

Comments _____

STAGE 2

Age 15 to 16 - Early High School Years

Transition Tasks	Completed	Date (MM/YY)
Detailed review of the Transition Resource List.	<input type="radio"/>	
Highlight resources relevant to the youth and family.	<input type="radio"/>	
If eligibility criteria for AISH are met, ensure all assessments are completed properly and on file.	<input type="radio"/>	
Continue dental health check-up (Check-ups every 6 months are recommended).	<input type="radio"/>	
Discuss puberty related changes and sexuality issues.	<input type="radio"/>	
Discuss social experiences with friends, dating and sex.	<input type="radio"/>	
Seek training and practical support for enhancing communication and social skills.	<input type="radio"/>	
Initial development and practice of daily living skills (e.g., personal grooming, cleaning of room, use of money, being on time).	<input type="radio"/>	
Develop post-secondary education plan.	<input type="radio"/>	
Pursue volunteer opportunities.	<input type="radio"/>	
Participate in community-based activities (social and recreational).	<input type="radio"/>	
Develop and practice skills for use of local public transportation.	<input type="radio"/>	
Determine if Health Insurance Plan of parent includes provision for medical care coverage for adult child.	<input type="radio"/>	
Forward application for PDD.	<input type="radio"/>	
Forward application for AISH.	<input type="radio"/>	
Discuss in more detail legal issues of Guardianship and Trusteeship.	<input type="radio"/>	
Obtain social insurance number.	<input type="radio"/>	
Open a bank account for personal savings/checking and obtain an ATM card if appropriate.	<input type="radio"/>	
Obtain a photo identification (ID Card).	<input type="radio"/>	
Begin discussion about future independent living arrangements.	<input type="radio"/>	
Document what resources are needed to support the vision for the future of independent living.	<input type="radio"/>	

Planning Timeline Summary

Date _____ Age of Child _____

Comments _____

STAGE 3

Age 17 to 18 - Later High School Years

Transition Tasks	Completed Date (MM/YY)
Discuss relevant resources from the Transition Resource List.	<input type="radio"/>
Continue regular visits and preventive care for medical health.	<input type="radio"/>
Confirm process of transferring medical and other health care records from current paediatric doctor to new doctor or adult clinic.	<input type="radio"/>
Continue dental health check-up visits twice a year.	<input type="radio"/>
Conduct mental health / addiction assessment (if appropriate).	<input type="radio"/>
Continue participation in social, sports or recreational activities.	<input type="radio"/>
Support building safe relationships with persons in the community through participation in volunteer roles, social, sports and recreational activities.	<input type="radio"/>
Discuss personal safety issues and self-advocacy skills related to social activities, sexual behaviour, and workplace contexts.	<input type="radio"/>
Review graduation requirements for high school.	<input type="radio"/>
Conduct vocational skill and career interest assessment.	<input type="radio"/>
Continued practice of daily living skills (e.g., personal grooming, cleaning of room, use of money, being on time).	<input type="radio"/>

Transition Tasks	Completed Date (MM/YY)
Confirm post-secondary education plans or employment plans.	<input type="radio"/>
Review application requirements for college or job training (if appropriate to plans); obtain any needed testing.	<input type="radio"/>
Conduct on-site visit to explore ASD supports available at preferred post-secondary educational or training settings (i.e., university or college campus).	<input type="radio"/>
Prepare a resume to use in job search.	<input type="radio"/>
Engage in part-time work or volunteer role to get early work experience.	<input type="radio"/>
Develop and practice automobile driving skills for use of private transportation (if appropriate).	<input type="radio"/>
Establish contingency strategies for a “Plan B” course of action if transition plans for education or employment become delayed.	<input type="radio"/>
Confirm eligibility to adult support programs (PPD/AISH; if relevant).	<input type="radio"/>
Visit potential housing options.	<input type="radio"/>
Confirm application requirements for housing and availability.	<input type="radio"/>
Complete paperwork to create legal Guardian (if applicable) to make decisions for non-financial needs of adult child.	<input type="radio"/>
Complete paperwork to create legal Trustee (if applicable) to make decisions for financial needs of adult child.	<input type="radio"/>
Meet with lawyer to create a Will for parent(s) that includes future financial support of adult child (if relevant).	<input type="radio"/>
Meet with lawyer to create a “letter of intent” that describes lifestyle preferences for desired care of adult child (if relevant).	<input type="radio"/>
Complete all other documents required for adult systems.	<input type="radio"/>

Planning Timeline Summary

Date _____ Age of Child _____

Comments _____

STAGE 4

Age 18 to 21 - After High School Years

Transition Tasks	Completed	Date (MM/YY)
Discuss relevant resources from the Transition Resource List.	<input type="radio"/>	
Start visits and preventive care for medical health with new providers in adult care system.	<input type="radio"/>	
Continue dental health check-up visits twice a year (need to find a new adult dental care provider?).	<input type="radio"/>	
Conduct mental health / addiction assessment (if appropriate).	<input type="radio"/>	
Encourage participation in social, sports or recreational activities in new contexts of college, training or work.	<input type="radio"/>	
Seek out resources in school or new community for continued training and practical support for enhancing communication and social skills.	<input type="radio"/>	
Encourage further development of personal safety issues and self-advocacy skills related to social activities, sexual behaviour and workplace contexts.	<input type="radio"/>	
Encourage building and maintaining connections to community and friendships. Recognize natural supports and foster opportunities for connections.	<input type="radio"/>	
If not graduated yet from high school, explore options for obtaining support needed for academic performance.	<input type="radio"/>	
Review graduation requirements for college or job training program.	<input type="radio"/>	
Review level of current progress toward graduation requirements.	<input type="radio"/>	
Meet with educational or training staff to review availability of and success of supports for ASD.	<input type="radio"/>	
Find a mentor or job coach for individualized on-going local support for school/work environment.	<input type="radio"/>	
Review of daily living skills and adjustment to housing arrangement.	<input type="radio"/>	
Meeting of parent, young adult and Guardian (once a year or more).	<input type="radio"/>	
Meeting of parent, young adult and Trustee (once a year or more).	<input type="radio"/>	
Meet with employer to review workplace accommodations for ASD.	<input type="radio"/>	
Seek counselling and support needed for self-advocacy and self-determination skills as young adult.	<input type="radio"/>	

Planning Timeline Summary

Date _____ Age of Child _____

Comments _____

Resource Appendix

This Resource Appendix provides contact information or links to government and community resources. It describes where to find specific programs, services, organizations, websites and other useful resources in Calgary and in Alberta. Most of these resources are also listed and updated on The Ability Hub website:

www.theabilityhub.org

In addition to this resource we recommend families visit the Transition Resources section of the Children’s Link website:

www.childrenslink.ca

General Autism Resources and Supports

AUTISM SPEAKS CANADA

Autism Speaks’ goal is to change the future for all who struggle with an Autism Spectrum Disorder by funding global biomedical research into causes, prevention, treatments, and a possible cure for Autism Spectrum Disorder. Autism Speaks has also published numerous tool-kits as resources for families of children with Autism.

1-888-362-6227 (toll free)
www.autismspeaks.ca (CAN)

ORGANIZATION FOR AUTISM RESEARCH (OAR)

This organization focuses on research that directly impacts the day-to-day quality of life of learners with Autism Spectrum Disorder, and promotes evidence-based practices.

1 (703) 243-9710
www.researchautism.org

AUTISM COMMUNITY TRAINING (ACT)

ACT provides information and training in accordance with international best practices. They enable parents, professionals and para-professionals to support children and adults with Autism Spectrum Disorder to live productive, satisfying lives within their families and their community.

1.866.939.5188 (toll free)
www.actcommunity.ca

Launch Domain #1: Health and Well-Being

General Health and Family Support

HEALTH LINK

Health advice from a registered nurse 24/7. They will ask questions, assess symptoms and determine the best care. They can also connect to other care professionals, including linking to a family physician.

Dial 8-1-1

www.albertahealthservices.ca/223.asp

AUTISM CALGARY

Offers recreational programs as well as a variety of support groups and social opportunities.

1 (403) 250-5033

www.autismcalgary.com

Mental Health and Psychoeducational Assessment

ACCESS MENTAL HEALTH

The role of Access Mental Health is to assist members of the community with navigating the addiction and mental health system and ensure they get to the right service at the right time.

1 (403) 943-1500

www.albertahealthservices.ca/11443.asp

CALGARY DISTRESS CENTER

Provides crisis support, professional counselling, and referrals to social services - at no cost.

1 (403) 266-HELP (4357)

(24/7 Crisis Line) or (403) 266-1601

www.distresscentre.com

FULL SPECTRUM INTERVENTIONS

Provides diagnosis, assessment and counselling services focused on ASD and co-existing mental health issues such as anxiety, depression, ADHD and OCD. Technology-focused interventions, supports and training.

1 (403) 282-1035

www.livingasd.ca

MCMAN CALGARY

McMan offers a wide range of family counselling and intervention programming. They have an FSCD funded Milestones program that offers behavioural and developmental aid to families with a member on the autism spectrum.

1 (403) 508-6259

www.mcman.ca

INTEGRATED SERVICES IN EDUCATION (ISE)

ISE offers high-quality psychological assessment, prevention and treatment services to improve the educational and psychological well-being of children, adolescents, adults and families.

1 (403) 220-2851
www.werklund.ucalgary.ca/ise

PSYCHOLOGISTS ASSOCIATION OF ALBERTA

Professional association for psychologists working in Alberta. Offers tips and guides for understanding and selecting psychology services, as well as a psychology referral service.

1 (780) 424-0294 or 1 888 424-0297 (toll free)
www.psychologistsassociation.ab.ca

Dentistry Needs

ALBERTA CHILDREN'S HOSPITAL PEDIATRIC DENTAL CLINIC

Treatment for special needs children from 0 – 18 years of age - sedation dentistry and anaesthetized dental work.

1(403) 955-7836
www.albertahealthservices.ca/services.asp?pid=saf&rid=1023475

FOOTHILLS DENTAL HEALTH CLINIC

A referral based dentistry service for developmentally delayed adults.

1 (403) 944-2401
www.albertahealthservices.ca/services.asp?pid=saf&rid=1023987

Physical Fitness and Weight Loss

SPECIAL OLYMPICS

Programs open to individuals of all skill levels with an intellectual disability ages 2 and up.

1 (403) 735-1022
www.specialolympicscalgary.ca

ALBERTA HEALTH SERVICES – NUTRITION COUNSELLING – PEDIATRIC OUTPATIENTS

Registered Dietitians provide general nutritional counselling for infants, children and adolescents, including healthy eating for optimal growth, allergies/food intolerances, breast feeding/formula feeding concerns, failure to thrive, and inappropriate diet for age or restricted diet that may lead to nutrient deficiencies. For anyone under 18.

www.albertahealthservices.ca/services.asp?pid=service&rid=5920

Sexual health

CALGARY SEXUAL HEALTH CENTRE

Offers services for people with developmental disabilities, both individually and in a group. They offer a maximum of 6 one-on-one sessions where counsellors discuss sexuality and sexual health. Parents or support workers are encouraged to attend the sessions.

1 (403) 283-5580

www.calgarysexualhealth.ca

Launch Domain #2: Education and Employment

Educational Supports

CANLEARN SOCIETY

A Calgary learning centre that assists individuals with educational challenges. Assessment and treatment of learning issues is offered - psychologists and pediatricians on staff. No referral needed.

1 (403) 686-9300 or 1-877-686-9300 (toll free)
www.canlearnsociety.ca

RENFREW EDUCATIONAL SERVICES

Renfrew offers a variety of educational services, respite, family support, early childhood intervention and more.

1 (403) 291-5038
www.renfreweducation.org

Employment Supports

CALGARY ALTERNATIVE SUPPORT SERVICES (CASS)

Offers a variety of programming, including the Calgary Alternative Employment Services (CAES) to help individuals with disabilities find and maintain work.

1 (403) 283-0611
www.c-a-s-s.org

CALGARY YOUTH EMPLOYMENT CENTER

Offers free career planning and job finding services for those aged 15 to 24. They can assist with portfolio, resume and cover letter development, interviewing, job searching, etc.

1 (403) 268-2490
www.nextsteps.org

CHAMPIONS CAREER CENTRE

Assists individuals with finding permanent employment (part-time or full-time). Offers assessment, career counselling, job search, job maintenance, workshops, skill development, employer connections, 1:1 support and more.

1 (403) 265-5374
www.championscareercentre.org

DDRC – CAREER AND LEISURE SERVICES PROGRAM

Provides part-time and full time support to adults with developmental disabilities in their communities as they work, join clubs, volunteer, and make friends in their communities.

1 (403) 240-3230
www.ddrc.ca

DRES – DISABILITY RELATED EMPLOYMENT SUPPORTS

Funds supports/services to assist Albertans w/ disabilities make successful transitions from school to work, unemployment to employment, etc.

1 (780) 422-4266 or 1 800 661-3753 (toll free)
www.humanservices.alberta.ca/working-in-alberta

PROGRESSIVE ALTERNATIVES SOCIETY CALGARY (PASC)

Offers the Progressive Employment Services (PES) program, which provides supports for individuals with developmental disabilities to connect to employers.

1 (403) 262-8515
www.pasc-calgary.org/progressive-employment-services

PROSPECT

Wide variety of programming, including adult day programs, with a vocational focus. They have various programs running throughout the day including art groups like Studio C, and employment programs.

1 (403) 273-2822
www.prospectnow.ca

VECOVA CENTRE FOR DISABILITY SERVICES AND RESEARCH

Vecova covers a broad range of service needs, including a recreation complex for adapted needs, and a bottle depot which offers a supportive workplace, hiring individuals with various special needs.

1 (403) 284-1121
www.vecova.ca

Post-secondary Programs Modified for Individuals With Disabilities

Inclusive Education

INCLUSIVE POST-SECONDARY EDUCATION PROGRAM (IPSE)

Supportive education for students with developmental disabilities, including modifications to assignments and tests to volunteer and employment opportunities.

Bow Valley College

1 (403) 410-1501
www.bowvalleycollege.ca/campus-services/learner-success-services/counselling-and-specialized-support/inclusive-post-secondary-education

Mount Royal University

1 (403) 440-6145 or 1 (403) 440-6384
www.mtroyal.ca/AcademicSupport/ResourcesServices/InclusivePost-SecondaryEducation

St. Mary's University

1 (403) 701-5284
www.stmu.ca/inclusive-post-secondary-education

University of Calgary

Practical Education with Employment Focus

SERVICE ALBERTA TRANSITIONAL VOCATIONAL PROGRAM

Post-secondary training to adults with mild developmental disabilities to help them prepare for the world of work and independent living.

1 (800) 661-3753

www.humanservices.alberta.ca

Website to Alberta Works Centres:
www.humanservices.alberta.ca

INTEGRATED TRAINING PROGRAM

Programs are designed to prepare students for employment in different sectors of the economy.

Columbia College

1 (403) 235-9300 or 1-888-235-9370 (toll free)

www.columbia.ab.ca/programs/integrated-training

Launch Domain #3: Communication and Social Relationships

Building Social Skills

AUTISM ASPERGERS FRIENDSHIP SOCIETY (AAFS)

Respite care in a recreational environment for children, youth and adults of all abilities

1 (403) 246-7383
www.aafscalgary.com

CHILD SAFE CANADA

Various programs such as ‘Chill Out’ for anxious youth, and other programs for self-esteem, social skills, etc.

1 (403) 202-5900
www.childsafecanada.com

PEERS: SOCIAL SKILLS FOR ADOLESCENTS AND YOUNG ADULTS

This program is an evidence-based social skills intervention for motivated adolescents (13-18) and young adults (18-28) who are interested in learning ways to help them make and keep friends.

peers@ucalgary.ca

General Social Groups

CALGARY BETWEEN FRIENDS CLUB

Provides unique opportunities for individuals with disabilities to have social interaction with peers who may or may not have a disability. Weekly activities, camps, etc.

1 (403) 269-9133
www.betweenfriends.ab.ca

Speech and Language Pathologists

ALBERTA SPEECH LANGUAGE ASSOCIATION OF PRIVATE PRACTITIONERS

This is one SLP association in Alberta. Their website is particularly helpful for searching by category, like developmental disability, and there are many listed who will also work with adults.

www.asapp.ca/slp-listings

Launch Domain #4: Independent Living Skills and Self-Advocacy

Public Transportation and Other Busing Systems

CALGARY TRANSIT TRAVEL TRAINING

Seniors or individuals with disabilities who are travel-trained will gain a sense of self confidence and independence when using Calgary Transit services.

1 (403) 537-7777
www.calgarytransit.com/accessible-transit/using-service/travel-training

ACCESS CALGARY

An accessible transit service for the Calgary area, which offers hand-offs at destinations as well.

1 (403) 537-7777
www.calgarytransit.com

DREAMS TRANSPORTATION LTD.

A private busing alternative to ACCESS Calgary. Dreams is based in Calgary, but operates virtually anywhere in Southern Alberta. Rates depend on distance, and Dreams will do their best to arrange multiple pick-ups in one area to reduce cost. They accept private pay, as well as FSCD and PDD billing, but the latter would need to be pre-approved. Aides ride for free.

1 (403) 590-RIDE (7433)
www.dreamstransportation.ca

Driver Education

AMA ALBERTA MOTOR ASSOCIATION DRIVER EDUCATION PROGRAMS

AMA is now offering an online driver training curriculum for individuals who may have challenges attending the in-class portion of driver training. AMA also offers free coaching sessions for parents of teen drivers, and in-car sessions with instructors who are supportive of disability.

1 (403) 240-5302 x 6558 or 1-800-642-3810 (toll-free)
www.ama.ab.ca

DRIVEABLE – DRIVING ASSESSMENT

Provide assessments for cognitively at-risk drivers using an in-office cognitive assessment tool and an on-road performance evaluation.

Requires referral from a clinician (physician, psychologist, etc.)

1 (403) 252-2243
www.driveable.com

Money Management

MOMENTUM WORKSHOP YOUTH FAIR GAINS

A free workshop for youth ages 16-21. Momentum will match the money you save so you can earn while you learn. Youth are taught to: Learn money management skills, create a budget and build your savings, build your credit, and more. Eligibility depends on household income.

1 (403) 272-9323

www.momentum.org/youth-fair-gains

MONEY MENTORS

An Alberta wide program that offers free online and in-person classes for learning how to budget, managing debt, increasing savings, understanding credit ratings, etc. They also have great information packages and budgeting sheets that can be downloaded from their website.

1-888-294-0076

www.moneymentors.ca

Community Programming and Respite Services

CALGARY PROGRESSIVE LIFESTYLES FOUNDATION

Provides Community Access, day programming, Employment Supports, Residential Supports and respite services. PDD funded.

1 (403) 276-1016

www.cplf.ca

JANUS ACADEMY

Janus offers educational services to children and adults with ASD.

1 (403) 262-3333

www.janusacademy.org

JUST 4 U FAMILY SERVICES

Provides respite care for families with special needs and typical children.

1 (403) 590-2122

www.just4ufamilyservices.com/child_services

STEPPING INTO LIFE INC.

This is a respite Service for individuals of any age that teaches L.I.F.E. Skills curriculum includes: address/telephone skills, community awareness, cooking, daily routines, job readiness, laundry, self-care and hygiene, and sports skills

1 (403) 295-2010

www.steppingintolife.ca

SUPPORTED LIFESTYLES AB

Offers a vast variety of services ranging anywhere from crisis relief to Day Programming and beyond.

1 (403) 207-5115

www.supportedlifestyles.com

Domain 5 – Legal and Financial Issues

General Legal Services

LEGAL AID ALBERTA

Legal services at minimal cost.

1-866-845-3425

www.legalaid.ab.ca

VANDERLEEK LAW

This firm has been practicing law for over 20 years, and has experience working with families with children with various disabilities.

1 (403) 457-4575

www.vanderleeklaw.ca

Guardianship

GUARDIANSHIP AND TRUSTEESHIP – OFFICE OF THE PUBLIC GUARDIAN AND TRUSTEE

The Adult Guardianship and Trusteeship Act (AGTA) is for adults over the age of 18 years who are unable to make personal or financial decisions for themselves.

1 (403) 297-3364 or 1-877-427-4525 (toll free)

www.humanservices.alberta.ca/guardianship-trusteeship

Range of options – Less intrusive options such as “supported decision making” or “co-decision making” to “full guardianship and trusteeship”.

CHILDREN’S LINK SOCIETY

Children’s Link Society offers help with guardianship, trusteeship, PDD, AISH, and navigating the system.

1 (403) 230-9158

www.childrenslink.ca

KERBY CENTRE CALGARY

Staff at the Kerby Centre assist with many aspects of adulthood and later adulthood. They also offer help with guardianship and informal trusteeship applications for individuals 18 and up.

1 (403) 265-0661

www.kerbycentre.com

Funding

ASSURED INCOME FOR THE SEVERELY HANDICAPPED (AISH)

Provides financial and health-related assistance to eligible adults with a disability.

www.humanservices.alberta.ca/disability-services/aish.html

FAMILY SUPPORT FOR CHILDREN WITH DISABILITIES (FSCD)

Family-centred supports and services to help their child's healthy development and encourage their child's participation in activities at home and in the community.

www.humanservices.alberta.ca/disability-services/14855.html

PERSONS WITH DEVELOPMENTAL DISABILITIES (PDD)

PDD funds programs and services to help adult Albertans with developmental disabilities to be a part of their communities and live as independently as they can.

www.humanservices.alberta.ca/disability-services/pdd.html

Immigrant Aid

IMMIGRANT SERVICES CALGARY

Formerly Calgary Immigration Aid Society. Offers various supports including assistance in completing forms, filing claims, and interpretation and translation services.

1 (403) 265-1120

www.immigrantservicescalgary.ca

DOMAIN 3 - COMMUNICATION AND SOCIAL RELATIONSHIPS

Goals**Strategies/Resources/Programs**

DOMAIN 4 - INDEPENDENT LIVING SKILLS AND SELF-ADVOCACY

Goals**Strategies/Resources/Programs**

DOMAIN 5 - LEGAL AND FINANCIAL ISSUES

Goals

Strategies/Resources/Programs

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