

## Youth with FASD Transitioning Initiative Toolkit

### Lakeland Centre for FASD



Enroute to Cold Lake, North East Alberta 2009

If one could envision this terrain a few years down the road, the evidence of new growth would be abundant.  
Nature teaches us a great deal about life. (Photo and text by Dorothy Badry)

The purpose of this toolkit is to offer some direction for youth with FASD transitioning to adulthood. The primary target group is young people who are in relatively stable living situations and have someone in their life that can support them in various ways as a young adult.

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### Lakeland Centre for FASD

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## **Table of Contents**

Introduction by Audrey McFarlane – Youth with FASD Transitioning to Adulthood

Introduction

A support network with regular involvement

Advocacy Casework

- A stable source of income for young adults with FASD
  - Resources for Income Support in Alberta
- A place to live and residential support Mechanisms to respond to crises
- Responding to Risky behavior sexual activity, health ,med management, relationship safety/peer pressure, medical care, disease management, substance use others
- Supported employment or alternative
- Community access and awareness

## **Introduction by Audrey McFarlane**

### **Youth with FASD transitioning to adulthood**

The Lakeland Centre for Fetal Alcohol Spectrum Disorder is a unique rural not for profit organization that is celebrating 10 years of business in 2010. The LCFASD has a reputation of working where individuals are at and moving them forward in a slow and stable manner through long term outreach models. The wrap around model of service includes diagnosis with a multidisciplinary team for children and adults; post-diagnostic outreach support; transition planning; employment coordination; mentorship for the highest risk women for having a child with FASD; education, awareness; resource development; and summer camp for kids with FASD. Through this work, many gaps in service have been identified for individuals with FASD, and the LCFASD works to find the best solutions to meet those gaps.

Many of the children who were diagnosed 10 years ago have now experienced transition to adult services. The families have struggled with making this shift as have our outreach workers. There is not a clear path for youth with FASD accessing supports for adults, nor is it well explained prior to 18 years of age. Many of our youth have experienced failure, unstable living situations, and trouble with the law, addictions, unemployment, and children they have difficulty caring for. This has been a troubling experience for everyone involved.

The LCFASD had developed a resource guide for service providers and families on the systems and contact people in the service area; however, this document did not seem to meet the needs of families or service providers. In an effort to determine how best to improve the situation, the LCFASD contacted Dorothy Badry for assistance to review the current literature on transitioning youth with disabilities to adulthood, determine what tools were available that might be helpful to the LCFASD and others, and make some suggestions as to considerations for planning for youth with FASD. The LCFASD was able to secure funding from Alberta Employment and Immigration in a partnership to address the needs of individuals with FASD.

The collaborative work of a team of individuals on this project has resulted in a great resource in which to understand transitioning to adulthood, what tools currently exist, and what we should consider when planning. Understanding the unique needs of youth with FASD and merging this understanding with resources available for a disability population is a helpful place to begin this work. The LCFASD has taken this information to expand our work in developing a unique planning process to promote stability for youth with FASD. This planning process builds a positive image of the youth and their realistic future possibilities by utilizing the support systems around them to gather information about the youth to build a road map for the future.

Many thanks to Dorothy Badry, Aileen Wight Felske, Deborah Rutman, Tobias Mwandala and Megan Tucker for their hard work and dedication to this project. Special thanks to Alberta Employment and Immigration for their foresight into the strength of youth and for identifying the need for better planning processes.

Audrey McFarlane  
Executive Director, LCFASD

## **Introduction**

The focus of this project was to identify the needs of youth with FASD who are transitioning into their adult life. For the purpose of this work, the population was identified as youth who were living in relatively stable places, such as adoptive homes, foster care or with supportive family, and who had supportive adults in their life in order to support negotiation of the transition from adolescence to adulthood, and from youth to adult services.

Support is a critical factor for young adults with FASD who find negotiating life in an adult world an event for which they are not fully prepared. Despite efforts at planned transition, supports do not always follow youth with FASD into adulthood. For children raised in the care of families, foster or group care, strict eligibility requirements for adult disability supports may exclude these individuals from similar services as adults.

Many youth with FASD living in Alberta are provided service in one form or another by Alberta Children and Youth Services, especially those youth who do not reside with their family of origin and are permanent wards of the province. As well, children who are raised in the care of Alberta Children and Youth Services and who have received supports related to a diagnosis of FASD must have a transition plan to adulthood developed by age 16. The need to establish frameworks that support life trajectory planning is critical, and it is recommended that early planning related to all life transitions be put in place early in the life of a child with FASD.

Recently, census data highlight the growing trend for young people to reside in the parental home well into their 20s (Statistics Canada, 2006). Moreover, Participation and Activity Limitations Survey (PALS) (2001) data indicate that young adults with disabilities live in their parental home longer relative to young people who do not have a disability. At the same time, youth who wards of the state (i.e., youth in foster care) must leave their placement when they reach age of majority, regardless of their personal readiness to live on their own. As numerous researchers have noted, these youth are required to transition to adulthood earlier, yet with fewer resources, than their age-based peers (Rutman, Hubberstey & Feduniw, 2007; Tweddle, 2007).

## **Project focus**

The purpose of this project was to offer information on topic of youth with FASD and to examine some key issues related to transition to adulthood. This topic is of growing importance as many youth reach adulthood, and families realize that support services provided to children and youth are not always available for young adults with FASD. In order to establish what has worked with youth in the past, an initial activity of this project was to conduct a review of both research and grey literature on the topic of youth with FASD and the life transition to adulthood.

It is important to recognize that the book has not yet been written that would offer a step-by-step plan for transition to adulthood. Nevertheless, many excellent resources exist.

Moreover, the province of Alberta has demonstrated strong leadership in multiple initiatives for individuals with FASD. For example, the Lakeland Centre for FASD, located in Cold Lake Alberta, offers a model of support that engages children and family in collaboration with communities and government. It is recognized that it takes an active community of support to see children with FASD through to adulthood (Van Bibber, 1997).

Key elements required to support youth in the transition to adulthood include features such as: a support network that has regular involvement with the young adult; Advocacy Casework, a stable source of income for the young adult, residential support, mechanisms to respond to crises; supported employment or alternative and supports related to community access and awareness. Each of these areas is expanded upon below in a way to support critical thinking about the transition-related needs of youth.

### **A support network that has regular involvement with the young adult**

Individuals with FASD require a committed circle of support. This means that the young person needs to have individuals in their life who are *available* to offer support on a regular basis. If a support network does not exist, the creation of a network is a critical tool and one that must be established as a priority. To establish a circle of support, the following steps offer a strategy:

- Determine who is available and willing to act in the capacity of support through contact with caseworkers, foster family or other community members involved in the life of the young person.
- Define what being available means, i.e. daily, once a week, once every two weeks, once a month and so on.
- Define the type of contact to occur – face to face, phone, electronic, regular visits on a particular night, a regular monthly meeting or activity. This must be clear and specific.
- Define what support means – is it social, financial, responding to a crisis? What will be offered? Determine that the person offering the support is acceptable to the young adult and preferably is someone with whom the young adult already has a trusting and respectful relationship.
- Being involved with an individual with FASD requires a commitment. What is the level of commitment that can be offered? Is it realistic, can it be maintained, is there a back-up plan?
- Engage in community mapping or community access and awareness survey. What natural supports exist in the community? Support the young person to complete a community access and awareness survey by going with the individual into his/her community to see the people with whom he/she has connections and how these connections function. This provides an opportunity to gather information about the community, the individual's awareness of the resources in the community (and/or possible negative influences in the community), and also offers a beginning place to develop community contacts and strengthen connections.
- Wight-Felske (2007) defined neighborhood mapping as follows:

*Neighborhood Mapping involves going to the community and identifying places that are important to the individual. A small map can be developed that includes photographs of these places where the person has a connection. Ask the individual to answer questions about the community in relation to places that are important to them, take photographs and insert these into a community map in order to have a visual picture associated with a particular place. A neighborhood or community map can continue to develop over time as the individual expands their links to the community. (p. 5)*

## **Advocacy Casework**

Advocacy casework is a construct that is focused on supporting the strengths of individuals with disabilities while managing those areas in which the person requires increased support. Areas where this is important for youth with FASD include:

- managing financial resources;
- supported independent living or other residential supports;
- employment;
- health support and management including physical, sexual activity/health
- emotional and mental health supports
- education; and
- community engagement.

In order to engage in effective casework with youth with FASD it is critical to recognize that youth with FASD often present well verbally, but may lack the capacity or resources to follow-through on commitments. Making commitments and not being able to follow-through is a frequent problem for youth with FASD and is often identified as a 'behavior' versus a disability.

## **A stable source of income for young adults with FASD**

The need for a source of financial support that covers the costs of basic needs (i.e., for food, clothing and shelter) is essential to stability for a young person with FASD. There are two inter-related needs/issues here: 1) the need for a reliable source of income/financial support; and 2) the need for reliable financial supervision.

If stable income is not maintained, other problems will follow such as homelessness and falling into an ongoing cycle of poverty. At the same time as there is need for a consistent course of income, there typically is need for support relating to managing income funds for youth with FASD. This is another component of advocacy casework and support.

Youth with FASD do not easily learn from their mistakes due to impairments in neurological processing that give rise to difficulties for the youth in retaining information based on previous experience. Social expectations exist such that a youth who is able to verbally present well is perceived as being as capable as the youth sounds in conversation. When youth who say all the right things make mistakes, the response from others is often

punitive. Further, because youth with FASD often struggle with both cause-and-effect thinking and the ability to generalize from one situation to the next, the notion that the young person with FASD will learn from being cut off from financial assistance does not work; rather, such a punitive approach contributes to the spiral of poverty that is frequently experienced by young persons with FASD who do not have a strong support system. Moreover, such an effect for a youth with FASD is a constant state of crisis, often fueled by poverty. These youth often expend their energy on dealing with these problems versus involvement in community-based activities that can support a positive quality of life. Individuals with FASD are easy victims to those who would take advantage of their financial resources. As such, there may be an ongoing need for vigilance and advocacy on the part of members of the youth's support network. In some cases, the need exists for trusteeship where the trustee disburses funds for rent and perhaps even grocery vouchers.

### ***Resources for Income Support in Alberta***

Income support in Alberta is administered through the Government of Alberta under *Employment and Immigration* <http://employment.alberta.ca/FCH/689.html> under the *Income and Employment Support Act* ([http://www.qp.alberta.ca/574.cfm?page=100P5.cfm&leg\\_type=Acts&isbncln=9780779725250](http://www.qp.alberta.ca/574.cfm?page=100P5.cfm&leg_type=Acts&isbncln=9780779725250))

Other supports for Albertans with disabilities include Persons with Developmental Disabilities (PDD) Community Governance under the Seniors and Community Supports Ministry (<http://www.seniors.gov.ab.ca/PDD/>).

### **A place to live and residential support**

A place to live that is safe and secure is essential to stability. While some youth will remain in their placement, such as in an adoptive or foster home, the need for supports in the transition to adulthood exists. Determining where a young person with FASD will live is an important process. Ideally, the young person will be in a home where there is awareness of both the risks and benefits for the individual. Awareness of potential risks may help to minimize such risks.

Planning for where the young person will live takes a substantial amount of time and should begin at least two years prior to the transition to legal adult age. Establishing trials in the new setting may be very helpful in order to support the transition. Youth in care may have options for remaining in their homes. Some young adults remain in their foster care or residential placement with supports from extended guardianship to age 21 (within Alberta). If this is an option, the extension of formal care offers time for increased maturity and gaining life experience. Whenever possible, an extension of care until age 21, or alternatively, the development of intensive supports should be considered a viable option for young adults. Recognition of the challenges faced by young persons with FASD, their

vulnerabilities and social problems offers a compelling case to offer more support versus less support. This requires a new framework for thinking about the needs of youth. Even though young people turn 18, their needs for support do not decrease and caseworkers should consider all options for ongoing support wherever possible. Counseling regarding residential options is an important role for the caseworker engaged in supporting the individual through the transition to adulthood.

## **Responding to Risky behavior**

Youth with FASD, especially those transitioning to some form of independence may require support in areas such as sexual activity and safety issues related to this area. There should be teaching and planning offered to the youth by a person he/she trusts to support a planned versus crisis approach to sexual activity. Other health related areas include support around medication management and tools such as packaging medication through a pharmacy or alternatively at home with a reminder system in place to take medications. This is critically important if the young person has some type of chronic medical condition. A plan related to medical care such as regular appointments with a physician or community health clinic are mechanisms to offer support and care. Additionally, if the young person has an acquired disease such as a sexually transmitted infection (STI) the need exists for developing a plan including follow-up supports for management of this health concern. Other areas of concern are around relationship safety/peer pressure and recognition of the vulnerability of youth with FASD in relationships with others. Due to the desire of the young person to 'fit in' and to feel connected to a peer group the risk exists that the youth will tolerate relationships that may include physical, sexual, emotional and financial abuse. These areas must be carefully assessed and awareness of the supports for the young person in collaboration with an understanding of their particular vulnerabilities may help to address these issues and develop safety plans. The other area of risk is engagement with substance use and the problems and risks associated with this behavior. Youth with FASD must be supported in all the above health related areas in order to minimize risk and support healthy living.

## **Mechanisms to respond to crises**

A young adult with FASD will undoubtedly experience different crises in their life, as do other young people who struggle with the responsibilities of adulthood. However, a person with FASD also most likely has multiple issues and life circumstances that can contribute to crises that are psychosocial in nature. In order to assist the young person in dealing with crises, a plan must be established that addresses the following:

- What is the nature of the crisis? What are the precipitating factors to the crisis?
- What are the emergent concerns that need to be addressed i.e. legal, financial, social, medical, mental health?
- Who is the person going to call when there is a problem? Does the person have all emergency contact information? Who else needs to have the contact information of the "first responder" in times of crisis?



- What supports are currently in place in order to respond early to a crisis? i.e. is there a weekly visit or a daily phone call that has been missed by the young person? What is the plan to respond to a missed contact such as a visit or phone call?
- What type of emergency response is required? Does someone the young person knows and trusts need to go and see the individual to respond to the problem or debrief the incident?
- Has a process or protocol been established in order to respond to a crisis? Establishing a protocol supports both the young person and his/her support people to know how to respond in the event of a crisis. One strategy may be having emergency contacts placed in the residence, a card that the individual carries as well as numbers pre-programmed into a cell phone. If the designated member of the support circle is not available in a crisis does the young person know alternatives such as calling the health link, hospital or police?

### **Supported employment or alternative**

Employment, volunteering or participation in a day program is often a very meaningful part of life for persons with disabilities. Many people go to work not only to support themselves, but to also have the opportunity to socially engage with others. Individuals with FASD have unique struggles in the workplace because problems related to organic brain injury are not readily visible or easily understood as a disability versus an intentional behaviour. Work can be very stressful for young persons with FASD if they are not adequately supported in the workplace. For young persons with FASD, there are particular vulnerabilities in the workplace that cannot easily be controlled for. The following case example illustrates some of the challenges in the workplace.

*Jim is 21 and has FASD. He has worked at the same restaurant for the past five years cleaning tables, replacing condiments and greeting customers. Joe is 19 and started working in the kitchen at the restaurant six months ago. Joe has the impression that Jim's job is easier and approaches the manager requesting to switch jobs with Jim. Joe suggests that Jim has worked there a long time and should have a 'promotion' to the kitchen. The manager who knew Jim well and had some awareness of his struggles left the restaurant a few months ago. He did not pass on the information to the new manager that the job Jim is currently doing is all the pressure he can handle. Jim knows his job, the routine and does it well. The new manager approaches Jim and suggests that he trade jobs with Joe and start working in the kitchen tomorrow. Jim does not recognize the potential problems with such a move and thinks the manager must know what he's doing because he's the boss. Jim started in the kitchen helping take plates out to customers. He got confused as to which table to take the plate, could not keep up with the speed required and multiple demands on him from several people at a time. Within one week Jim loses his job after five years because he cannot handle the multiple pressures of working in the kitchen. This is a real case example.*

In deconstructing this example it is apparent that Jim got lost in the system through a series of miscommunications. No one could have anticipated that Joe might throw a wrench into a system that was working well. Perhaps Joe took advantage of Jim, but those in charge of the workplace lost a long-term employee through placing expectations on Jim that he could not manage. In part, this scenario reflects the multi-faceted complexity of FASD. Jim had

stability in his job for five years and there was no work plan that was put in place to ensure that he remained secure in a position that he could handle. In reflection, it is clear that some kind of documentation/communication that could be passed onto the new manager may have helped in this situation.

In the absence of paid employment, other opportunities and/or regular activities need to be established. This could take the form of some type of further education, volunteer work, classes that support skills, talents or interests of the individual. It is important to establish a system of transportation that will allow the individual to access community based activities. It is important to determine who will be responsible for supporting the young adult with attendance at these activities by ensuring a stable means of getting to and from home to the community. In combination, involvement in some kind of physical activity also provides opportunities for socialization and health promotion. These types of involvements offer additional structure to support the individual. At the same time, the support needs of adults with FASD in terms of setting up these activities, getting to and from them, and/or being accompanied at these activities need to be fully recognized as critical to participation and community access. It is important to explore funding opportunities that may be available within the community such as recreation passes. If the young person is able to receive some form of financial support the budget should, wherever possible, include recreation and other social activities.

### **Community access and awareness**

Having a connection and knowledge about one's community is a critical part of community living. Having neighbors and being able to engage in the local community supports engagement and a sense of belonging. There are various local resources that can offer various activities and services such as the library, community recreation centre, churches and local establishments such as restaurants or coffee shops. These are places where people meet others and can become actively participating members.

A list for neighborhood mapping that an individual could explore can be established based on the local community. The list will vary dependent on the community. Based on the list one could ask the young person what they would like to explore in the local area. This familiarity with community helps to maintain connectedness to place. Becoming familiar with various forms of transportation, emergency services and medical supports are also important for safety. It is also important to establish that the individual knows what to do, who to call or where to go locally in the event of some kind of emergency or crisis. What local community resources exist and how are they accessed? Establish a call list for local support.

## Supporting Caregivers

This resource list includes resources that have been identified as offering support specifically related to caregivers, families and professionals supporting youth with FASD in various transitions in their lives. This list is not exhaustive as many resources are available on the World Wide Web (WWW). The “home base” of the resources identified is geographically located in Western Canada.

FASD Support Network of Saskatchewan Inc.

<http://www.skfasnetwork.ca/Network%20Resources%20&%20Materials.html>

Lifeguard Strategies for Supporting Adolescents and Adults Affected by FASD

[http://www.skfasnetwork.ca/pdf%20files/LifeguardStrategies\\_web2010.pdf](http://www.skfasnetwork.ca/pdf%20files/LifeguardStrategies_web2010.pdf)

Provincial Outreach Program for FASD (British Columbia)

<http://www.fasdoutreach.ca/elearning/assessment-networks>

This website includes e-learning modules on different aspects of FASD including Learning about FASD, Essential Tips, Planning Instruction, Creating a Positive Behavior Climate, Teaching to Strengths and Needs and Developing an Individual Education Plan.

Enviros FASD Support Program (Alberta)

[http://www.enviros.org/index.php?option=com\\_content&view=article&id=55&Itemid=67](http://www.enviros.org/index.php?option=com_content&view=article&id=55&Itemid=67)

Manitoba FASD Centre

<http://www.fasdmanitoba.com/FASDBrochure.pdf>

Fetal Alcohol Family Association of Manitoba

[http://www.fafam.ca/htm/fafam\\_links.htm](http://www.fafam.ca/htm/fafam_links.htm)

Can Northwest FASD Research Network

<http://www.canfasd.ca/>

Government of Alberta FASD Demonstration projects

<http://www.child.alberta.ca/home/875.cfm#CommunityJusticeProgram>

Government of Alberta FASD Links Page

<http://www.fasd-cmc.alberta.ca/home/links.cfm>

When Youth Age Out of Care – Where to From There?

A final report by Deborah Rutman, Carol Hubberstey and April Fedduniw with assistance from Errin Brown

<http://socialwork.uvic.ca/docs/research/WhenYouthAge2007.pdf>

Centres of Excellence for Children's Well Being [Youth Focus]

<http://www.engagementcentre.ca/>

*The Centres of Excellence have developed a series related to youth concerns, engagement and supports in relation to life decision making. The constructs and ideas presented in this series present important ideas about understanding the needs of youth, risks they take and offers information on decision-making and the importance of adult allies. These are important concepts for all youth and present an inclusionary framework.*

What is Youth Engagement?

[http://www.engagementcentre.ca/files/Whatis\\_WEB\\_e.pdf](http://www.engagementcentre.ca/files/Whatis_WEB_e.pdf)

Youth Taking Risks: Is it all in our heads?

[http://www.engagementcentre.ca/files/Whatis\\_WEB\\_e.pdf](http://www.engagementcentre.ca/files/Whatis_WEB_e.pdf)

let Discussion Guide us: Decision Making – How should children and youth participate in decisions about them?

[http://www.engagementcentre.ca/files/YDMGuide\\_web\\_e.pdf](http://www.engagementcentre.ca/files/YDMGuide_web_e.pdf)

Adult Allies in Action

[http://www.engagementcentre.ca/files/alliesFINAL\\_e\\_web.pdf](http://www.engagementcentre.ca/files/alliesFINAL_e_web.pdf)

Youth Engagement: A conceptual model

[http://www.engagementcentre.ca/files/alliesFINAL\\_e\\_web.pdf](http://www.engagementcentre.ca/files/alliesFINAL_e_web.pdf)

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