

**April 5, 2006**

**EXPLORATION OF PERSONS WITH DEVELOPMENTAL  
DISABILITIES (PDD) SERVICES IN ALBERTA FOR  
PEOPLE WITH  
FETAL ALCOHOL SPECTRUM DISORDER (FASD)**

**Prepared by Audrey McFarlane  
Executive Director**

**LAKELAND CENTRE FOR  
FETAL ALCOHOL SPECTRUM DISORDER**

## **GOAL OF THIS PAPER:**

To highlight the difficulties that individuals with a diagnosis of FASD, who qualify for PDD services, face in accessing adult services and why this is. To stimulate the discussion on how to better serve these individuals.

The LCFASD is one of the few places in Canada that adults that have been pre-natally exposed to alcohol can obtain a diagnosis. Given this, it puts our adult services in a leadership role in determining how best to serve these individuals. In the PDD world several important beliefs govern the delivery of services and function to improve the quality of life for individuals with developmental disabilities. What if some individuals with developmental disabilities have needs that clash with those very beliefs? This is what appears to happen for individuals with FASD thus leaving both the system and the individual feeling frustrated.

This paper will explore these beliefs, what this can look like in an individual with FASD, and why this happens.

The LCFASD continues to have a strong and positive relationship with the Northeast PDD community board and staff, and are beginning the work to explore different options for individuals with FASD. This paper is to stimulate discussion not to offend or place blame on a wonderful organization that has done tremendous work to support our adults with developmental disabilities to be contributing members of our society.

*It should be noted that the LCFASD does not have the answers on what the best practices are for adults with FASD because the research has not yet been done. The LCFASD would like to begin the exploration of what might be possible and try some theories with PDD.*

*Others are free to use this paper to explore better solutions for individuals with FASD by giving credit to the author.*

### **Typical young adult with FASD**

For the purpose of this paper we will keep in mind the characteristics of a typical adult today with FASD trying to access services.

- Young adult
- Not had many specialized services in the past, including childhood
- No guardian
- Minimal family involvement, may not be a positive influence
- Traumatic life
- Experience with justice
- Poor memory
- Poor judgment
- Looks more capable than they are
- I.Q. and functional deficits that qualify them for PDD services.

**Individuals must want services**

What that looks like for someone with FASD	Why
<ul style="list-style-type: none"><li>❖ Not showing up for appointments</li><li>❖ Not calling to request services</li><li>❖ Not calling to set up appointments</li><li>❖ Verbally says all the right things</li><li>❖ No follow thru</li><li>❖ Appears unmotivated</li><li>❖ Identified as difficult</li></ul>	<ul style="list-style-type: none"><li>▶ Poor memories</li><li>▶ Easily distracted</li><li>▶ Does not have insight to see the need for services</li><li>▶ Not used to having specialized services</li><li>▶ May not have a stable system to assist them</li></ul>



Reality: Without an advocate the individual is unable to access services. They will likely end up in more trouble with the law, homeless, and likely an early death without interventions.

**Individuals must be involved in  
planning for services**

What that looks like for someone with FASD	Why
<ul style="list-style-type: none"> <li>❖ Not attending meetings, meetings rescheduled and frustration builds on both sides</li> <li>❖ Verbally grandiose</li> <li>❖ Sounds like they know what they want</li> <li>❖ Everyone works hard to make the plan happen and then they don't want this but something completely different, and they are not grateful for the efforts</li> <li>❖ Individuals is frustrated by the length of time systems take, this can be anger and then is viewed as being difficult and not really wanting services.</li> <li>❖ Individual has difficulty managing the group discussions</li> </ul>	<ul style="list-style-type: none"> <li>▶ Poor memories</li> <li>▶ Unable to predict</li> <li>▶ Unable to envision the future</li> <li>▶ Unable to plan ahead</li>   <li>▶ Verbally sounds good but often does not understand what they have said or remember what they have agreed to</li> <li>▶ The plan that is developed is only good for that day – can't visualize , can't remember, and does not see the significance of the meeting</li> <li>▶ Does not have insight into how systems work</li> <li>▶ Difficulty following conversations in group situations</li> </ul>

**Individuals direct their own services**

What that looks like for someone with FASD	Why
<ul style="list-style-type: none"><li>❖ A different plan frequently</li><li>❖ Looks manipulative</li><li>❖ Never satisfied, always wanting something different</li><li>❖ Unrealistic expectations</li></ul>	<ul style="list-style-type: none"><li>▶ Unable to predict into the future</li><li>▶ Not enough structure/routine/consistency</li><li>▶ No insight into own needs</li><li>▶ Verbally capable but they have minimal comprehension</li></ul>

**The goal is independence, to reduce services over time**

What that looks like for someone with FASD	Why
<p>When the individual is stable, staff begin to reduce supports &amp; increase expectations</p> <ul style="list-style-type: none"> <li>❖ Decrease productivity</li> <li>❖ More avoidance or away time</li> <li>❖ Looking for other interests (less healthy)</li> <li>❖ More argumentative</li> <li>❖ More shut downs or outbursts</li> <li>❖ Loss of privileges as imposed by staff</li> <li>❖ Development of a behavioral plan</li> <li>❖ Loss of placement when they don't respond to the loss of privileges or behavior plan.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Staff/workers/helpers become the cue in their environment, the persons guide.</li> <li>▶ Once this cue is removed they lose balance, the cue, and are unable to remember on own</li> <li>▶ No insight into needing this so respond in a reactive/survival manner</li> <li>▶ Better to look bad than stupid</li> <li>▶ Unable to articulate needs</li> </ul>

**Structure/Routine/Consistency  
forever is viewed as a loss of  
independence**

What that looks like for someone with FASD	Why
<ul style="list-style-type: none"> <li>❖ Individual must do chores/clean/cook as an example</li> <li>❖ Sometimes they can</li> <li>❖ When they can't they can be belligerent/argumentative/or run away</li> <li>❖ Viewed as behavior problem</li> <li>❖ Staff try to talk the person thru or into the task can make things escalate</li> <li>❖ Frustration builds between staff and individual</li> </ul>	<ul style="list-style-type: none"> <li>▶ Individuals with FASD have good days and bad days</li> <li>▶ Inconsistent memory in the best of situations</li> <li>▶ Not have insight to see benefits of completing tasks</li> <li>▶ Not able to rationalize into remembering</li> <li>▶ Can't do these things vs won't</li> </ul>



Reality:

Adults with FASD need a “do for”, someone to do for them when they can not

**Allow people to fail and learn from their mistakes**

What that looks like for someone with FASD	Why
<ul style="list-style-type: none"> <li>❖ Repeated trouble with the law with escalating crimes</li> <li>❖ Homelessness</li> <li>❖ No finances</li> <li>❖ May develop alcohol /drug problems</li> <li>❖ Frustrated by staff</li> <li>❖ Staff blaming the individual</li> <li>❖ Health problems – poor eating choices</li> <li>❖ Children that they may not be able to care for</li> <li>❖ Poor relationship choices</li> <li>❖ Episodic reinforcement to staff when they can do things</li> </ul>	<ul style="list-style-type: none"> <li>▶ Do not learn from their mistakes</li> <li>▶ Impulsive</li> <li>▶ Do not remember</li> <li>▶ “Not their fault” (no insight)</li>   <li>▶ Only learn from mistakes when it is very traumatic and may be short term impact.</li> </ul>

**People are in control of their behavior**

What that looks like for someone with FASD	Why
<p>Behavior management techniques using positive and negative incentive/rewards programs look like:</p> <ul style="list-style-type: none"> <li>❖ Individual is able to use incentives for a short period of time then they are not effective</li> <li>❖ Once behavior is established and incentive is removed, the person does not continue the desired behavior</li> <li>❖ Incentive needs to be changed regularly</li> <li>❖ Individuals look manipulative and unreasonable</li> <li>❖ When behavior management programs don't work staff/agencies get frustrated</li> </ul>	<p>What if individual with FASD are not in control of their behavior as we understand it.</p> <ul style="list-style-type: none"> <li>▶ Impulsive</li> <li>▶ Lack insight</li> <li>▶ The incentives don't intrinsically develop a desire to complete the target behavior – it is the incentive that gets things done which gets stale over time and needs to be changes regularly</li> <li>▶ The need for structure/routine/consistency is more stable and predictable than any behavior mod program</li> </ul>

**Families are good supports**

What that looks like for someone with FASD	Why
<p>In some cases individuals with FASD have families that look:</p> <ul style="list-style-type: none"> <li>❖ Unpredictable</li> <li>❖ Uninvolved or uninterested</li> <li>❖ “Poor influence on individual”</li> <li>❖ “Different cultural beliefs”</li> <li>❖ Make poor choices</li> <li>❖ Don’t respond to written correspondence</li> <li>❖ Don’t show up for scheduled meetings</li> </ul>	<ul style="list-style-type: none"> <li>▶ Adults with FASD often come from parents who are FASD</li> <li>▶ Families may still be in the cycle of addictions</li> <li>▶ Families have distanced themselves from the individual because of the burnout and difficulties of raising a child with FASD</li> </ul>

Other difficulties:

- ▶ Staff cross over – working with individuals with Developmental Disabilities and then individuals with FASD creates expectations for FASD individuals that they can not meet and thus the placement breaks down over time.
- ▶ Agencies are deeply rooted in the Developmental Disabilities beliefs and find it very difficult to switch modes or see things from a different perspective when working with individuals with FASD
- ▶ Agencies are deciding that they may not want to serve individuals with an FASD diagnosis

The Lakeland Centre for FASD has been providing post diagnostic outreach supports to adults with FASD for about a year. A formal evaluation of this project will be completed next year but some early themes have been emerging around all the service systems. The following is the early learning's specific to the PDD system.

1. PDD mandate for services is vague.
  - It is difficult for families who have never had specialized services before to understand what PDD does and what they offer.
  - It is difficult for unhealthy families to access services.

Therefore, several individuals with FASD that meet the PDD eligibility criteria are unable to easily access services and thus are left on their own to function in society.

2. PDD & other agencies are not responsive to the needs of families when the parents are FASD
  - A whole family approach to service delivery is needed.
  - Many generations of families are FASD because of the generational nature of alcoholism.

In conclusion:

This paper has identified several key areas that are problematic when serving adults with FASD who are PDD eligible. This also highlights several areas that could be exciting to develop new ways of doing business, such as developing functional service plans, direct access to service, and new program delivery supports for these individuals. These are opportunities that can be built upon by others.

The adult service systems need to prepare themselves for all of the children that have been diagnosed in Alberta in the past year that will be turning 18 in the years to come. At this time several hundred children are diagnosed in Alberta each year. If we can develop adequate systems of service then we could potentially reduce the number of adults in the justice system, homelessness, women shelters, and emergency services. What a fantastic opportunity!

Audrey McFarlane  
Executive Director  
Lakeland Centre for FASD