Report on Supportive Housing Opportunities for Adults with FASD

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Background

Adults living with Fetal Alcohol Spectrum Disorder (FASD) can face multiple barriers and challenges in their attempts to secure one of the most basic of needs, appropriate housing. For many adults with FASD, access to supports and services that assist with daily living is futile without the foundation of adequate housing. Adults living with FASD display as many variances in their abilities and deficits as the spectrum disorder defines. The housing needs of this population also vary according to the degree of central nervous system damage and the presence or absence of secondary disabilities that are predominant in so many adults with FASD. A range of housing options is needed to establish a framework of stability and security for these adults, which can be as variable as their strengths and challenges. Despite individual differences in their disabilities, there is common ground among all in their need to have supported, safe, stable, consistent and affordable housing.

There are few supportive housing options for caregivers of youth with FASD when planning for transitions from adolescence to adulthood. The absence of suitable housing resources during this critical period shifts the weight of providing supported housing to the biological, adoptive or extended family, if the youth or adult is fortunate enough to have these resources. Sadly for many, the roof over their head is often a correctional facility, short-lived stay with family or friends or, drifting into a homeless cycle and living on the streets.

Optimally, when adults with FASD have their housing needs met the some of the burdens on their caregivers is minimized and the affected individuals can begin to focus on options for other areas of their life. Various emerging models of supportive housing for adults with FASD are being explored and developed in communities across Canada (Burns, C. 2008; Brownstone, L. 2005). Some of these models are transitional housing, others allow residents to build home equity through ownership, and many are specific for individuals such as single parents, males in the justice system or those struggling with addictions. Low-barrier housing offers some housing solutions for those who cannot meet certain eligibility criterion prior to accessing housing, such as

being drug and alcohol-free, or participating in rehabilitation programs. Unfortunately, a common link with many housing projects is lack of sustainable, start up funding, staffing challenges, inaccurate perception or a lack of understanding of FASD by the neighbourhoods or communities where the residents live, and the ineligibility of FASD clients meeting supportive living program guidelines (i.e. based on functional and/or I.Q. levels). The effectiveness of housing models is most evident when the service delivery meets the needs of the individuals and communities being served. Ultimately, an understanding of the disability, the presence of strong community and stakeholder partnerships, removing many of the barriers that exist before one is eligible for housing and having sustainable funding are paramount for successful housing outcomes for adults with FASD.

This report will examine options for supportive housing for adults with FASD, with specific reference to the Lakeland-Cold Lake service area. Information includes: 1) an overview of issues facing this population, including secondary disabilities; 2) a brief description of the geographic service region as it pertains to this topic; 3) challenges in the absence of appropriate housing; 4) description of current social housing resources in the area and the discussion of the need for supportive housing for adults with FASD; 5) opportunities and challenges for development of supportive living resources in this region.

Adults Living with FASD: Why is it so difficult?

Over recent years there has been documentation of the struggles that adults with FASD face. Many currently diagnosed children and youth entering the transitional stage to adulthood have been receiving housing, financial, educational or program support and services prior to adulthood. For those in the foster care system, housing was a provision that was not usually placed on the youth to secure. When many of the youth in this system turn the age of majority (in Alberta, 18 years old), many of the resources provided to them come to a sudden halt. There is much debate over the level of planning or preparation given to youth with special needs or disabilities who are exiting child welfare systems and having to navigate the process of finding housing that will support them. For young adults with FASD, the task can be daunting, especially when the resources in their community are absent. Adults who may be affected by FASD or those who have never received a medical diagnosis, are often entrenched in systems that do not understand their disability or do not have the services or supports that can assist with their needs, such as housing. Even though these individuals do not always have a formal FASD diagnosis, or they are considered to be "higher functioning", most are just as vulnerable in developing secondary disabilities as those with a medical diagnosis of FAS.

"**Primary disabilities are those that the child is born with. They reflect the CNS (Central Nervous System) dysfunction inherent in the diagnosis. Secondary disabilities are those that an individual is not born with and that could presumably be ameliorated through better understanding and appropriate interventions" (Streissguth, A. 1997).**

The following statistics shed light on the magnitude of issues and prevalence of those living with FASD:

***The rate of FASD in North America is estimated to be 1/100 or 1% of the population (includes full FAS, Partial FAS and Alcohol Related Neurodevelopment Disorder (ARND). This estimate is considered conservative.** (May, Gossage. *Estimating the Prevalence of Fetal Alcohol Syndrome, Alcohol Research and Health.* The Journal of the

National Institute on Alcohol Abuse and Alcoholism, Volume 25, Number 3, 2001; Sampson, Streissguth, Bookstein, Little , Clarren, Dehaene et al., *Incidence of fetal alcohol syndrome and prevalence of alcohol related neurodevelopment disorder.* Teratology, 1997)

***The average IQ in FASD is between 75 and 85, with the full range in FASD between 20 and 140+. Almost all individuals with FASD have an AQ<70 (adaptive quotient, measure ones ability to function day to day without supports in the areas of communication, socialization, daily living, time management, employment, etc.).** *(Russel, IQ—It Just Doesn't Matter: The Role of Adaptive Functioning in Individuals with FAS/FAE/ARN*. FASD Conference: Doing What Works, Vancouver 2003)

***For adults with FASD, 80% are unable to live independently, regardless of IQ. (Streissguth, Bar et al.** *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE); Centers for Disease Control and Prevention Grant no. RO4/CCR008515)*

***The apartment/Rental Accommodation profile for Cold Lake as of September 2005—0.6%**

***In a report by the City of Cold Lake Economic Development Advisor Committee Affordable Housing Report (2006), affordable housing gaps were listed as priority and identified the need for supportive housing for those with disabilities.**

At age 18, a new set of obstacles and challenges meet these young men and women, yet the supports identified as being necessary and lifelong in nature often fall short. Copeland and Rutman (1996) researched issues facing adolescents and young adults with FASD. Participants, their caregivers and involved professionals were interviewed and findings looked at "...specific impact that FAS/E has on learning, independent living, pregnancy and parenting and dealing with the human services systems" (1996:65). Ann Streissguth, a leader in FASD research at the University of Washington, has done much to heighten the awareness of prenatal exposure and its impacts for later development in the lives of those affected.

A four year study on secondary disabilities looked at six different identified secondary disabilities in the research population, ages 6-51 years old (Streissguth, Barr, et al., 1996). These included: mental health problems, disrupted school experiences, trouble with the law, confinement (i.e.: jail, mental health programming, inpatient drug or alcohol treatment programs), inappropriate sexual behaviour, alcohol and other drug problems.

This study also recognized other common occurring secondary disabilities in adults with FASD that put them at risk, including: being under employed; victims of violence; parenting and relationship issues; and inappropriate or absence of housing.

Nathan Ory describes cognitive factors in adults with FASD. (Why adults with FASD don't get better...What you see is not what you get. March 2004, *Adults with Fetal Alcohol Spectrum Disorders: Swimming Upstream, A Reality Check. Vancouver, BC)*

These cognitive factors include:

*Wide range between relative strengths and weaknesses (Looks and sounds "smart", acts disabled).

*Wide variability of function within day/week.

*Fluctuating attention and ability to focus.

The challenges in locating and maintaining basic housing for adults with FASD are at times insurmountable and unrealistic. For an adult with no disability, the task of finding rental or other housing in a tight rental market can be daunting, even when they are utilizing strong organizing, communicating, budgeting, decision making and problem solving skills. Adults with FASD often face frustration and confusion with the task of finding appropriate housing, and at times this can be compounded by landlords unwilling to rent without references, background checks and security deposits. Often these adults are not seen as having a disability and for many that are undiagnosed with the disorder they may not be eligible for supported housing resources. With lack of planned transitions or available adult resources or supportive housing, they may have to rely on family to provide the residence piece of the puzzle. This can result in families being financially burdened, with absence of respite resources to access, and being faced with a fear of not knowing who will provide safe housing for their adult child when family is no longer able to.

When adults are struggling with secondary disabilities, the business of finding supportive, safe, affordable housing is difficult unless communities have a plan and can provide appropriate resources to meet the spectrum of needs.

Most supportive housing for adults with disabilities is defined as being a shared home or group homes models. In some supportive housing resources, residents may have met eligibility criterion to receive a designated number of hours per week of support from individual workers, such as Person's with Developmental Disabilities (PDD) contracted services. In many of these instances, adults with FASD are living with family or are living in independent housing, with few other constant onsite resources. Group home models are not always the most appropriate choice of those with FASD, even if they are eligible for this type of housing. Housing and outreach programs that offer a variation of on and off site support, and an environment of social cohesion , efficacy and a sense of belonging and pride in their community are optimal goals for programs and agencies looking at housing solutions for this group of adults. Throughout Alberta, including Northeast Alberta, groups are looking at developing strategies to provide alternative models of delivery for those adults challenged in finding appropriate supportive housing.

Service region—Potential for services and programs

The Lakeland area, including Cold Lake, Bonnyville, Lac La Biche, Smokey Lake, St.Paul , the seven surrounding First Nation Communities and four Metis Settlements is expanding and has seen economic and population growths over the recent years. In 2006, the City of Cold Lake had a population of 11 991, with 8.7% identified as aboriginal. In 2007, the population had grown to 12 860, with 38.5% of the population aged 18 – 40 years. The economy base is strongly linked to the military base at Cold Lake and oil and gas exploration. The majority of people living in Cold Lake have single residence dwellings, with low rental vacancy rates. One bedroom apartments exceed $600.00/month rent; the rental allowance for a single person on AISH is $255.00/month. Bonnyville, located between Cold Lake and St. Paul, has a population of 5896 and has continued to see a growth in industry and population. St. Paul, population of 5100, has a solid economy base of agriculture and service industry and some oil and gas related employment.

The communities within this region have established human services agencies and not-for- profit groups that provide a spectrum of services for seniors, disabled, youth with special needs, and the unemployed. There is potential for these communities to be leaders in models of supportive housing for adults with FASD, as Lakeland Centre for FASD (LCFASD)has strong connections with stakeholders in the area and a proven record of providing resources and programs for supporting youth and adults with FASD.

The service region of Lakeland Centre for FASD's diagnostic clinics and other programming include Cold Lake, Bonnyville, Smokey Lake, St. Paul, Lac La Biche, and seven surrounding First Nation and Metis communities. Lakeland Centre for FASD provides mobile FASD diagnostic clinics for youth and adults throughout the Lakeland service area, with a unique service delivery model to rural communities. Since the year 2000, LCFASD diagnostic clinics have seen 254 children and 45 adults throughout the region. In addition to diagnostic clinics, LCFASD continues to provide FASD awareness, education, prevention campaigns, and continuum of care service for the diagnosed and their family. The Society also delivers evidence based training to

service providers, caregivers and professionals across the area. However a solid knowledge base in the community and awareness of issues for those with FASD does not always translate to provisions at the community level for appropriate supportive housing for adults with FASD. Currently in the north east region, where do adults living with FASD access housing?

What Happens in the Absence of Appropriate Housing?

Based on interviews with current service providers and agencies in the region it appears that supportive housing specific for these adults is very limited and in some communities, non-existent. Lakeland Centre for FASD Adult Support Coordinator Final Evaluation 2004-2007 identified a lack of supportive resources for Adults with FASD in the Lakeland region and explained that current resources for adults with disabilities were not always useful or appropriate for adults with FASD (Stonehoker, D., 2007). This evaluation report also states that FASD clients experience, "significant barriers to accessing services that may be appropriate for them for any number of reasons."

Typical barriers to these services include:

...personal issues that make FASD clients difficult to work with—past criminal experiences and incarcerations, volatile outbursts, addictions, history of non-compliance, or not following through with and requirements..." (Ibid, 2007)

Adults living with FASD also face challenges within the systems they need to work with in the search for any housing. Scenarios they face can include:

- a lack of understanding of behaviours presented by those with FASD by the service providers;
- stereotypes and fears of those with FASD;
- cultural biases;
- the revolving door of service agencies, new workers assigned and the exhaustion on the part of the client to have to tell their story over again each time they are referred to a different agency or worker;
- no relevance or substance to the action plans or recommendations by service providers that is applicable to some adults with FASD (i.e. given an application process for Social Housing that won't meet their needs or is beyond their capacity to complete);

- lack of flexibility for services for this population or the “one size fits all with disabilities” approach;

- difficulties in following through with supports for this population due to secondary disabilities— (homeless, drug/alcohol issues, underemployed, school disruptions in early life, victims of violence).

A reality for many adolescents and adults with FASD is often substandard housing with intermittent or chronic homelessness. The Alliance to End Homelessness defines what many of these adults face:

> **...as living on the streets, staying in a shelter, living in places not meant for human habitation (such as cars), or “couch surfing”—moving continuously between the homes of friends, family or strangers.”**

One alternative for parents or caregivers of affected individuals to meet the housing needs of these adult is to purchase a second residence. This is a costly and stressful means of providing alternative housing independent from the family home, where much of the financial and other supports for the individual rest with extended family. This alternate housing can be a mobile home, townhouse, apartment or basements suite, but it rarely offers comprehensive, multi-disciplinary, interdependent or on-site support for the adult.

Adults with FASD can be overwhelmed or oblivious to the necessities of budgeting, shopping, household maintenance, social relationships and boundaries, and other skills needed for maintaining and keeping successful housing. Social isolation, lack of direction for daily living tasks, minimal monitoring and mentoring and frequent breakdowns in their living accommodations are common. There are countless stories of immediate family members left dealing with unpaid rent or utility bills, costs of other moves and assisting with crises on a regular basis when there are inadequate supports.

A report by J. David Hulchanski (2000) on homeless individuals speaks to those who are “inadequately housed”. This certainly captures many adults with FASD who by definition may not be classified as being homeless; the prevalence or actual numbers of

adults with FASD who are counted as homeless are uncounted because of the difficulty in identifying those who are living in substandard, inadequate housing or being supported by burned out families or caregivers. The report goes on to state:

"Not all people who have their own place to live are adequately housed. People have the human right to adequate housing. All Societies have the obligation to make progress on the adequate housing of all people. Being inadequately housed, therefore, is not the same as being homeless, but it can lead to being at risk of houseless ness."

In a 2004 housing study in Edmonton, housing preferences for homeless individuals were identified. Although the study was not specific to the adult FASD population, it did capture a common need among the homeless: "There is clearly a preference in all homeless groups for basic, independent housing with financial and other supports, both in the short term and the long term." (Gardiner, H., Cairns, K. 2004 *Edmonton Joint Planning Committee on Housing. Summary Report, 2004.)*

It should be noted that rural or small communities are not immune to inadequate housing. The optics of homeless individuals, particularly those who are dealing with addictions or a dual-diagnosis, is often seen as an issue mainly centered in larger urban areas, such as Edmonton or Calgary and that it is non existent or not as prevalent in smaller communities. Factors that could influence the non-reported numbers of adults needing supportive housing in smaller, rural areas could be related to fewer numbers of emergency, short term supportive housing resources at a rural level, along with increased local family and community knowledge of individual needs of those with FASD.

Overview of Current Housing Resources in the Lakeland Region

Prior to looking at new or innovative models of supportive housing for adults with FASD, it is important to have some background on current housing resources and models of supportive housing operating at the local level. Awareness of current resources, understanding the gaps in services throughout an individual's lifespan, and examining models that are working well can assist those looking at developing supportive housing models and strategies for this population of adults.

Person's with Developmental Disabilities (PDD) in north east Alberta contracts with Catholic Social Services (Bonnyville/Cold Lake regions), Dove Centre and WJS Alberta to provide residential, supportive Independent Living Program services and life-skills, employment support for adults with disabilities. The Supported Independent Living Program serves adults with development disabilities who live in their own home and require supports; the Approved Home Program matches individuals with approved proprietors in the community. WJS has seven shared living or group homes in the service region and also provides individualized supports in the clients' homes, workplace or community. Services are dependent on clients meeting PDD criterion (www.ne-pdd.org).

Many adults with FASD are not able to meet PDD criterion for services. If they do qualify, opportunities for services may not be realized due to the inherent nature of the process prospective clients need to go through to access the supports. In many cases these adults will not understand or even be aware of the avenues to service access or application process and may not have the capacity to complete the necessary paperwork, make or keep appointments without guidance or follow through with planning in the absence of ongoing supports prior to the PDD approval process.

The need for assertive outreach and alternative options for housing are needed to assist those who are not aware of available formal or informal supports for housing and do not have a support network of family or others to help them access housing options. For many adults with FASD who are homeless or at-risk- being homeless, intervention or

options for housing must be brought to them through assertive outreach. The presence of barriers to accessing housing will be discussed in more detail further in the report

Catholic Social Services

Catholic Social Services (CSS) provides and manages resources within the Bonnyville-Cold Lake region for adults with disabilities, which can include those with FASD and is one example of PDD funded supports in the area. Presently this service provider oversees six residential resources located in Bonnyville and one located in Cold Lake. Included is one larger group living home that can accommodate six adults; 4 smaller group living homes that can accommodate 3 – 4 adults with disabilities; one group living home in Cold Lake with a 3 – 4 resident capacity, and a one -level,5 unit, semi-independent apartment complex that has separate, independent units located in Bonnyville.

The 5 -unit semi-independent resource is owned by the Bonnyville Affordable Housing Association, but is managed by CSS. The Supported Independent Living Program, funded by PDD, provides supports for residents in the group care homes and apartment; therefore it is a criterion for all residents to be eligible for PDD services. The age range of clients served are between 25 years – 80 years old; the range of disabilities also ranges from total 24 hour care and supervision to those who might receive a few hours /week of independent living supports from their assigned worker.

The smaller group living homes in both communities are rental houses, which are usually found by CSS staff. Tacey Murphy, a program manager with CSS in Bonnyville states there is an advantage in developing strong community contacts and having good knowledge of resources in the region. Building rapport and relationships with various landlords in the local area are invaluable in locating suitable rental housing for these adults.

There is a screening process to match the adults living together, with personality and interest questionnaires taken into account. Each individual has a choice as to whether they will live in the rental accommodation. The staffing is shift-staffing, rather than a

house-parent model (personal communication: Tacey Murphy CSS, Bonnyville, AB, Jan. 15, 2009).

As explained by Tacey, there are demographic differences between Cold Lake and Bonnyville and these differences have some influence on housing availability, cost of rental accommodation and differences between service delivery time–frames for clients in the two communities. Bonnyville is the location for many established oil and gas industry businesses and for the most part, has a population base that is multi-generational and less transient than in Cold Lake. It was noted that the clients that CSS serves in Bonnyville tend to be longer-term than those they have in Cold Lake resources. Both communities deal with housing shortages.

The residential resources operated and managed by CSS are not specific to adults with FASD however they do have adults with this disability that utilize their resources. Again, these individuals need to be eligible for PDD services before they can access any of the housing options.

The five-unit semi-independent housing building in Bonnyville was built to be inclusive for those with disabilities. Each individual unit has a separate bathroom and kitchen-living space, and there is a common area where group social events, meals, entertainment and recreation activities can take place. Support resources are not on site 24-7, but rather are in place for each individual resident through their PDD individual support plan. This support is dependent on each resident's particular needs. According to Tacey, "one of the greatest successes is keeping a roof over their heads and for the residents to have the security of not being moved or evicted from one month to the next" (personal communication, Jan. 15, 2009). For adults living in these units and who are affected by FASD, CSS sees success and a positive response to the support offered to them as tenants. The long term relationships and education building that is established within the community has allowed some grace to be shown to the tenants. If these individuals were living in a regular rental arrangement, where other residents or landlord might not have an understanding of the secondary disabilities of an adult with FASD, the challenges that come with independent living could be

compounded with complaints and evictions that ultimately lead to the homeless cycle. In this semi-independent resource, CSS acts as a buffer for the landlord, which is Bonnyville Affordable Housing. In scenarios that could lead to crises, frustration and be cause for eviction, CSS has implemented plans to diffuse and deal with certain issues that are fairly commonplace and predictable with some of their tenants with FASD.

Some examples are when tenants inadvertently or otherwise set off the fire alarm (CSS has good communication with the local fire department) or when they misplace or lose their apartment keys on a regular basis (one of the CSS group homes across the street always has replacement or extra keys available 24-7). There are other times when CSS is able to assist the client with minor repairs or maintenance which could otherwise be overlooked or neglected in other rentals. With knowledge that these scenarios involve residents who may not have a strong sense of cause and affect, face deficits with executive functioning and abstract reasoning and having a landlord that knows their actions are not intentional or malicious, conflicts and crises can be anticipated and averted.

The common area in this 5- unit resource also provides a space for social interaction and group activities, both of which can alleviate some of the isolation and loneliness that are common in unsupported environments. For many of these adults, providing a safe, adequate physical space does not always meet the need for positive social interactions or the ability to provide support for meaningful daily routines or activities. If they are not employed, participating as a volunteer or have other perceived relevance of their use of time, many of the issues relating to addictions, justice involvement, inappropriate social relationships, mental health or health management problems can quickly fill their time.

Cold Lake Affordable Housing Society

Cold Lake Affordable Housing Society (CLAHS) facilitates the provision of affordable, adequate and accessible housing for the Cold Lake region (www.clahs.org). A current project is being developed that will see an additional 32 mixed residential units available for low – moderate income levels. Eight of the 32 units will be leased to the Dr.

Margaret Savage Crisis Centre and will provide up to 12 months of secure, affordable housing for women and their children who are leaving a violent environment. The Society will own the building, but will contract a property manager. Criterion for rentals in the building will be income -based, providing a criminal record and background checks. There are no supports provided to the tenants, other than supports or training for the eight units designated for the Dr. Margaret Savage Crisis centre clients.

CLAHS does not have a mandate to provide social housing specific to adults with FASD or other disabilities, as their foremost goal is to provide affordable housing to those in need. The lack of specific social housing projects or supportive housing by this Society does not equate or indicate a lack of understanding by their staff for the housing needs of adults with a life-long disability, such as FASD. Similar affordable housing groups are found in Bonnyville, St.Paul and developing in Lac La Biche.

Lakeland Lodge and Housing Foundation

This group has mandates of social housing and facilitates the rent subsidy program for eligible clients living in Bonnyville and Cold Lake. Currently, there is a waitlist of between 20 –23 for social housing in Cold Lake. Criterion for social housing is based on income level, with the majority of tenants being eligible for the Assured Income Support for Handicapped (AISH) eligible. Prior to accepting an applicant and offering a tenancy agreement, there is an application process, interviews with family members, references checked and income criterion forms completed. It was stressed that the this particular social housing resource is affordable housing for those individuals who can manage independently and can function on their own, without being dependent on day to day supports. No ongoing, onsite supportive assistance is provided to the tenants. Presently in Cold Lake there are 12 social housing units and none currently located in Bonnyville.

The rent subsidy program provides assistance to those who would qualify for social housing, but have managed to secure a rental accommodation on their own. An example would be a single, AISH qualified client, who is entitled to $255.00/month for accommodation/rental allowance. If the rental rate is $1000.00/ month, then the

difference between their AISH entitlement and the actual rental cost can be eligible for the rent subsidy. In Cold Lake, there are currently 15 low income individuals receiving rent subsidy, with the majority being on AISH. As with the Cold Lake Affordable Housing Society, this foundation sees a gap in emergency, transitional or supportive housing for adults with disabilities, including those with FASD.

Challenges and Opportunities for Supported Housing Models for Adults

Prior to any discussion of affordable, supportive housing models for adults affected by FASD, it is important to look at the fit between the individual and the supports being offered, as well as understanding the variances in behavioural symptoms that exist with those with an invisible disability. Most successful projects or supported housing initiatives have the underlying premise of respecting each individual's right to dignity, privacy, a safe environment, involvement in the housing community, an active participant in decision making and other quality of life topics. Affordable housing is not just about providing a building to house people; it is about the people who live there.

When dealing with supportive housing for adults with disabilities, specifically those with FASD, there are some core value-based questions that can affect many issues that face this population.

Some of these issues query opposite or opposing ends of spectrums of interventions, such as inclusive vs. integrated housing being the best fit for adults with FASD; harm reduction models of intervention vs. providing services when client is clean or sober for a pre-requisite period of time; goal of providing life-long supports or accommodations for individuals vs. providing supports that will lead to independence and assimilation into mainstream society. When examining the responses to core values and its impact on housing service delivery models for adults with FASD it is paramount for support agencies and those mandated to provide housing to have a solid understanding of the disability and how prenatal alcohol exposure can affect the central nervous system. They should also have some knowledge around the ramifications of brain-based behaviour and development of secondary disabilities for those affected.

One cannot assume that adults who lack adequate or supportive housing will be proactive in accessing these appropriate resources. For many adults with FASD, their experiences with finding and maintaining adequate housing has been less than

desirable or non-existent. One alternative that has been suggested for adults with severe addictions and /or mental illnesses is low barrier housing.

While this model does not specifically serve only adults with FASD, it is understood that many adults with FASD suffer from addiction and mental health issues.

> **Low barrier housing (most often transitional with a strong harm reduction philosophy) has recently emerged as a housing and support option for people with severe addictions and or Mental Illness (SAMI). The low barrier housing model recognizes that the SAMI population faces a wide range of challenges related to housing including locating accommodations, securing a damage deposit, signing a lease or simply producing identification (Patterson, M., Somers, J., McIntosh,K., Shiell, A., Frankish, C.J. 2008)**

Inherent values in all models of housing supports for adults with FASD should include those that encourage community engagement and stakeholder involvement, which is necessary for long term success and sustainability. These stakeholders can include the private sector, not-for profit organizations, faith-based groups, and certainly should involve those affected by this disability, including those adults affected and their caregivers. According to the PDD Aboriginal Policy Framework, one of PDD's guiding principles describes partnerships within a framework of community inclusion for services for Alberta's aboriginal population living with developmental disabilities. The partnerships and stakeholder involvement cited below is relevant for any adults with disabilities.

> **Optimal results will be achieved through a range of partnerships, between PDD, at the Ministry and Community board levels, and entities such as First Nations/Aboriginal Groups, federal and provincial government Ministries, local Authorities, and service providers**
> (www.pdd.org/docs/prov/AboriginalFramework2006.pdf)

Building relationships with stakeholders in the community can lead to less fragmentation of services and encourages a multi-disciplinary model of services.

Range of Service Models

The complex housing needs of these adults cannot be addressed with a singular one – size- fits all response, but rather needs to look at the effectiveness of a range of housing models. It is important for criterion to not exclude those adults who may not have a formal FASD diagnosis, but who are certainly affected and need life-long supports to maintain appropriate housing. For many adults who have been affected by prenatal alcohol exposure, a medical diagnosis is not the norm and for them the link between supportive services being provided when they lack a formal diagnosis has been absent.

Hopefully, with new provincial FASD initiatives and the Alberta Cross Ministry FASD Service Networks, the infusion of sustainable dollars to support expanded diagnosis and continuum of care for both children and adults will provide less roadblocks and barriers for adults living with FASD.

There is research that indicates there are positive outcomes when individuals understand how they were affected by FASD. Being aware of and understanding why certain learning styles are present and being able to access support for learning accommodations for those with an organic brain injury can increase self-esteem and help them make sense of their world (Rutman, D., La Berge, C., Wheway, and D. 2002).

Outreach—foundations for stability

Agencies and service providers should be knowledgeable about the difficulties and challenges these adults face when offering housing choices for adults with FASD. Some of these challenges are behaviour –based issues and can be disruptive in the context of lack of housing supports. Strategies that can adapt and make accommodations, encourage self-control and esteem in the clients, and increase prevention of secondary disabilities are worthwhile endeavours of housing supports. These strategies are best implemented before any conflicts arise and when disputes and issues can be averted or anticipated. An expectation from most landlords is tenants use their better judgement and decision making skills based on social norms or

unspoken rules. Some examples of landlord expectations are: respecting others' personal space and boundaries; appropriateness of guests allowed in the building; paying your rent or utilities on time; being responsible for your physical space and acting within other acceptable societal expectations; maintaining a certain level of housekeeping and maintenance standard. These expected behaviours and actions are difficult to achieve when adults with FASD are not adequately supported or lack any guidance or intervention resources that assist with daily living skills. For many supported housing projects, having on-site support makes the difference of preventing homelessness. The grass-roots or foundation to any supportive housing planning or placements is often dependent on assertive outreach programs which pro-actively seek out individuals in need, rather than the client initiating the services. While this outreach service may not be the mandate or responsibility of organizations such as PDD, it can dovetail and complement PDD programs that support adults with FASD. There are initiatives that provide outreach workers for those at risk of being homeless and for those who may need stabilizing and advocacy prior to placement in supportive housing.

British Columbia Housing has partnered with community agencies to provide connections with homeless individuals. This client-centred approach sees,

> **"...housing staff work in conjunction with community providers to engage individuals...and link them to appropriate services and housing. Outreach workers undertake a wide range of support activities:**

***Address immediate physical and safety needs, such as food, warm clothing and a place to stay;**

***Connect people with housing and income support, including making and accompanying them to appointments;**

***Provide links to other support services, such as life skills training, personal health or household and financial management;**

***act as a landlord liaison. (www.bchousing.org)**

In north east Alberta, there are agencies that have capacity and knowledge of working with adult with FASD or who have the mandates of providing outreach services to this population. The agencies or other groups that provide ground-level supports could be stakeholders and partners with PDD programming for those adults having difficulty securing and maintaining appropriate housing due to secondary disabilities. As mentioned earlier, housing provides necessary stability prior to other supports being offered.

Transitioning to Adulthood—Housing needs

When youth affected by pre-natal alcohol exposure reach the age of majority (age 18 years in Alberta), the notion of them being able to access suitable housing and eventually become independent and function day to day with no supports is unrealistic for many. This expectation can also set them up for lifelong disappointments of facing revolving doors of temporary housing, homelessness, or placing the responsibility on other adult caregivers. Agencies that provide services to youth with a disabilities, particularly when the youth is a ward of the government, are responsible for developing transition plans to prior to the youth reaching adulthood. The goals of case management or planning should look at provisions for housing and plans for support into adulthood, and assurance that levels of support will not be temporary or fleeting for those needing continuation of services past their discharge from care. When putting the discharge plan in place, logistics such as the young adult's financial limitations, wait times for housing or availability of resources in their community, and criterion for accessing adequate housing. All of these issues can influence future standards of supports for these youth. There are existing assumptions around young adults with FASD and their ability to function independently after the age of 18. An unrealistic picture or misunderstanding of the disability and focusing only on the behaviour of the individual without the benefit of understanding the motives behind the behaviour can actually cause more harm. Inappropriate referrals may be made to employment or job readiness courses, cognitive or behavioural models for working on issues, or short-term or emergency housing. Many of these well-intended referrals to programs have the an assumption that adults with invisible disabilities will be able to function independently as long as they stay out of trouble and try hard. This model is skewed, as it is dependent on the young adult having the ability to make changes in their adaptive functioning and does not take into account any central nervous system damage, knowledge or accommodations that would be helpful to assist them with daily tasks and the permanency of the life-long challenges that they will face. When case managers who are responsible for youth affected by FASD begin to question and search for supported or other optional housing that might provide these resources, appropriate models can

be developed in partnership with agencies responsible for services for those with disabilities.

Case planning with youth who are approaching adulthood should look at their housing needs and strategies for support long before the age of majority is reached. For some youth, supported housing may be necessary prior to their 18th birthday. It is hoped that young adults will remain out of the scope of justice and legal systems, poverty or homelessness, and that agencies providing housing supports are pro-active and have mandates to begin planning prior to adulthood.

Communities should be aware of their demographics and the pending number of possible diagnosed children and youth with FASD, know where these youth are currently living, and examine the options that are available for them in later years. LCFASD provides FASD diagnostic services for youth and adults in north east Alberta communities and their capacity for diagnosis increases each year due to program expansions, provincial funding availability and increased provincial targets for diagnosis of youth and adults.

Being aware of the number of adults in the region that meet PDD criterion and also have FASD diagnosis is timely when discussing supportive housing for the region. In most communities, there is also an understanding that no one agency or group is entirely responsible for providing the many levels of care and support needed for adults with FASD.

Provincial Models of Collaborative Housing Responses

The standard for FASD diagnosis in Canada outlines the use of multi-disciplinary diagnostic teams who bring information to the diagnostic clinician, assisting with necessary background information about the client and to assist with concrete continuum of care recommendations for post-clinic follow-up (Chudley et al., 2005). Supported housing efforts also need to be seen as multi-disciplinary or collaborative in nature. In Prince George, BC the Northern Family Health Society completed a supportive housing feasibility study that looked at approaches of dealing with the housing issues for those living with FASD (August, 2007). This report states:

...a supported housing framework offers the opportunity for a housing strategy to emerge from the building of capacity of resources that already exist in the community and to offer multiple points of engagement.

The report goes on to describe the advantages of looking at present resources in the community as a beginning focal point and to set sights on building new projects or housing structures later if needed.

The BC Provincial Homelessness Initiative (PHI) through BC Housing allocates funding to developments that integrate subsidized housing with supports services for people who are homeless or at risk of being homeless; those with mental illnesses and physical disabilities; those with drug and alcohol addictions; aboriginal peoples; youth; and women fleeing abusive relationships. Other towns and cities in BC have developed the concept of converting single occupancy hotels in downtown core areas for affordable housing, with a spectrum of multi-disciplinary supports available to residents. There is 24-hour security, treatment and support options including addiction, medical and mental health resources.

The premise is to provide stable housing and then begin to deal with some of the listed issues. (www.bchousing.org/programs/homelessness).

Alberta's Community Based Homeless Initiatives partner with other levels of government, municipal organizations, private and not-for-profit housing sectors to provide effective, long-term housing solutions to seven major cities and communities in Alberta. Some of these initiatives could be developed in other areas of Alberta, such as the north east region, as there are already established sustainable housing societies and Lakeland Centre for FASD, which has a broad knowledge base regarding adults with FASD. In 2007, Wood Buffalo region developed a 3 year plan to address some of the assets and gaps in regional housing (Stubbs, T. et al., 2007). Three principles that guided implementation of the report were:

*to ensure the safety and security of individuals and families (provide food, clothing, safe shelter)

*to provide a continuum of care approach

*work with other community stakeholders to achieve partnership between sectors and agencies

Communities that are beginning strategic planning and discussions about supporting adults who typically do not fit the criterion for many housing resources, such as adults with FASD, need to develop guidelines that will assist with the parameters of housing issues for this population.

In Red Deer, Alberta, the Canada-Alberta Affordable Housing Program provides funding for The Buffalo Project. This housing initiative is a partnership between the not-for-profit Potter's Hand Housing Society, and Canadian Mental Health and has been operational for about one year. It is based on a Housing First philosophy, a response to homelessness which initially began in New York City as a means of getting people off the street and into housing as a first priority.

The Buffalo Project follows the goals of this philosophy by providing a low- barrier, harm reduction model for tenants who are cognitively impaired, have an acquired brain injury, and certainly includes many who are living with FASD. According to Sheila Dodge, Housing Manager with the Housing First program in Red Deer, there is a wide

spectrum of disabilities and needs amongst the tenants, with most dealing with addictions and mental illnesses. She states around 95% have addiction issues and around 80% need support in dealing with mental health issues.

Those with the most severe needs are at the top of their list; there are no cognitive level or alcohol/drug free criterion for admissions before accessing the housing (Personal Communication, Sheila Dodge, January 22, 2009). This low or no-barrier approach ensures that those who are most needy are provided housing and then supported based on individual assessments.

The Housing First premise is to build relationships with the tenants and provide a collaborative approach to care and support. Support from onsite, front-line tenancy support workers is available 24 hours a day, seven days a week. These workers are experienced with addiction and mental health issues and provide a full continuum of support to adults who have a range of secondary disabilities and who have experienced chronic homelessness. There is also a monthly psychiatric clinic onsite for tenants. As Canadian Mental Health is an approved PDD service provider, this agency employs the individual workers for those tenants who are eligible for PDD services. The Buffalo Project is located at an old downtown hotel in Red Deer and is a work-in-progress, with ongoing renovations to the units. Currently, there are 25 independent bachelor suites, with the potential for a total of 40 suites. The Potter's Hand Society owns the building and acts as the landlord.

The most current Buffalo project that is also onsite is a newly developed vocational training program available for eligible tenants. This Hospitality Industry Training Program provides targeted training in the service industry. This opportunity is managed for positive completion by participants, increasing success by having the program operate onsite in the building where the residents reside. Instructors and program coordinators have a level of understanding regarding students' the strengths and limitations. Upon completion of the program, there are employment opportunities for participants within The Buffalo Project by working in food preparation for the other tenants or with other appropriate employers.

Opportunities for North East Region of Alberta

There is much potential and a range of opportunities for regions throughout Alberta to explore housing partnerships with agencies, government bodies or funded agencies, not-for-profit or grassroots organizations and to begin discussions around a wrap-around supportive housing model for adults with FASD. The business community, community colleges, Municipal Affairs and other interested stakeholders are all part of the solution as regions direct attention to building capacity for social and supportive housing for adults with a disability. A supported housing program that can also accommodate vocational or other training and serves the needs of both tenants and the community is a win-win for both parties.

Much can be learned from examining other projects that are operational and often began from the same place as most—to provide appropriate, sustainable housing with supports for individuals needing mentorship, companionship, life-skills and other direction, respect and an interdependent model of care and shelter. It is recognized that many of these individuals will require permanent, life-long supports.

The starting point for any groups investigating housing solutions for these adults is to examine current community supports and assets and to have a thorough knowledge of demographics and the population that requires these supportive housing services. Knowing the numbers of youth and adults diagnosed with FASD in the region; the numbers of youth transitioning to adulthood and who are under a current model of care by government bodies; and the communities' capacity for emergency, short term and long term housing for adults with a disability are all important statistics that will drive the need for certain resources. Not all communities, even within a geographic region, will have the same needs for services. Stakeholder and other community support will also dictate the level of services that can be developed.

Partners and stakeholders sitting at the table during discussions of supported housing should be multi-disciplinary in nature, due to the variance in needs of this adult population. Agencies that are responsible for post-release or discharge planning from correctional facilities, hospitals and addiction resources are essential continuum of care

planners that can offer much in the way of long-term supports needed to encourage stable housing rather than the revolving door back to the jails, treatment centres or the streets. As is the case with most collaborative planning, there needs to be an established body identified to take the lead and focus on the integration of supportive housing services for those with this disability. Measurement of success for housing will be the number of clients living in suitable resources. This will take a concerted effort by all agencies working together. For the most part, this population of adults may not pro-actively seek out housing resources, so the system needs to accommodate this.

Potential communities that are ready to develop supported housing strategies should be prepared for the stigmas attached to the homeless and housing stereotypes that are prevalent for those who live in supported housing and have a disability. The tolerance level or lack of can become apparent when neighbourhoods are the site for planned housing.

Local and regional education and knowledge are key components of any supported community housing plans. PDD and other agencies are excellent resources for encouraging community awareness and participation to lobby government and educate others regarding the housing dilemma.

Municipalities and other agencies can learn helpful best practices and lessons from other successful housing projects in the province. Examination of regulatory solutions to housing, such as building codes, staffing, hotel conversions to individual units, secondary suites in homes, streamlining building permits, zoning for housing, and accessing agricultural land outside city limits can be instrumental in providing creative options for improving affordability, accessibility and success for supportive housing for adults with FASD.

Edmonton's Jasper Place Health and Wellness Centre received funding for permanent housing programs for the most vulnerable in the city. Certain processes are put into place for residents in this program. The finances of the tenants are overseen by the centre's staff; they agree to regular follow up visits with centre staff and are asked to not

have their apartment act as a drop- in for their friends. Jasper Place also adopts the Housing First Philosophy (Zabjek, A. Edmonton Journal, Jan. 27, 2009).

> **"The Centre has 10 housing support workers who typically have 20 clients to manage every week ...but before support workers can worry about keeping a client in an apartment, they have to find them one. That involves tirelessly canvassing apartment listings and building relationships with landlords. Landlords might be willing to take a less-than-ideal rental candidate if they know...staffs are there to backstop any problems" (Edmonton Journal, Jan. 27, 2009).**

If a permanent building is not available for supported housing, support workers could potentially build relationships with understanding landlords, with the assurance that adequate supports and resources are ongoing for their tenants. This solution might prove difficult in geographic areas that have a very low vacancy rate and expensive rental costs. Another indicator of success is often the difference of the location of supportive housing. When some tenants move to housing that is outside their usual location, the disassociation from old contacts can encourage positive mentorship and treatment potential for drugs and alcohol treatment.

A program that is funded by Canadian Mortgage and Housing Corporation and delivered by the Federation of Canadian Municipalities is ACT (Affordability and Choice Today). This program provides moderate grants for informing others on housing solutions or funding to host workshops to discuss innovative and successful models of housing. It also provides an excellent resource for regulatory solutions to a variety of housing solutions (www.actprogram.com).

Perhaps one of the strongest assets for the northeast region of Alberta with regards to resources for adults with FASD is the Lakeland Centre for FASD and the partnerships and programming the centre has developed in the communities within its service region. Partnerships with agencies that are able to provide expertise in training, programming, and delivery of services for a specific population are valuable stakeholders in any discussion of housing provisions in the region. LCFASD has developed relationships

with various agencies in the region, including PDD, and has in-kind contribution and participation on their youth and adult FASD diagnostic clinics. The Northeast region is the locale for many provincial pilot initiatives and a newly developed Provincial FASD Network, which provides mentorship for vulnerable women of child-bearing years, FASD diagnostic services for youth and adults and a continuum of care, support follow up for those affected. There are many other agencies and organizations in the region that will be pivotal in discussing housing for adults with FASD.

Conclusion

The intent of this report is to shed light on the housing needs of the most vulnerable in our society, including those who often are not aware of their need for supportive, safe and affordable housing that will serve their life-long needs. Development of housing for adults with FASD is navigating unchartered waters for many organizations; however there appears to be a will from all levels of government, agencies, and community to look at positive solutions to homelessness. Increasingly, we are seeing Society's expectation for housing that provides more than a short-term warehouse approach, with little sustainability. The short term model ultimately leads to the increase in homelessness and secondary disabilities seen in so many adults with FASD. The shift to low-barrier, housing-first strategies that offer life-long supports makes economic sense and allows communities to develop resources that match their unique needs. Supportive housing for adults with FASD requires stakeholder involvement with a range of community partners. The northeast region of the province, served by PDD, has a wide range of supportive housing models to examine both within and outside the region. The goal is to match the appropriate model to the needs of their clients. It is recognized that solutions will not be created over a short period of time and that quick-fixes rarely last the test of time for adults that require life-long supports.

Dialogue and discussions around housing for those living with FASD must be ongoing and involve all agencies responsible for provision of this most basic need. Creative options, including hotel conversions, location of interdependent housing and various levels of support and entry points for tenants must be explored as alternatives. Training for staff is essential when working and coming alongside adults with FASD, as conventional standards of intervention may not be always appropriate with this population. Ongoing evaluations and having an agency directly responsible for steering stakeholder response to homelessness is important to keep the goals on track to and for plans to not get lost or misguided over time. There are numerous models of supportive housing to evaluate across the country; choosing a direction that will serve the needs of PDD's north east region might serve as a best practices approach for other areas of the province.

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