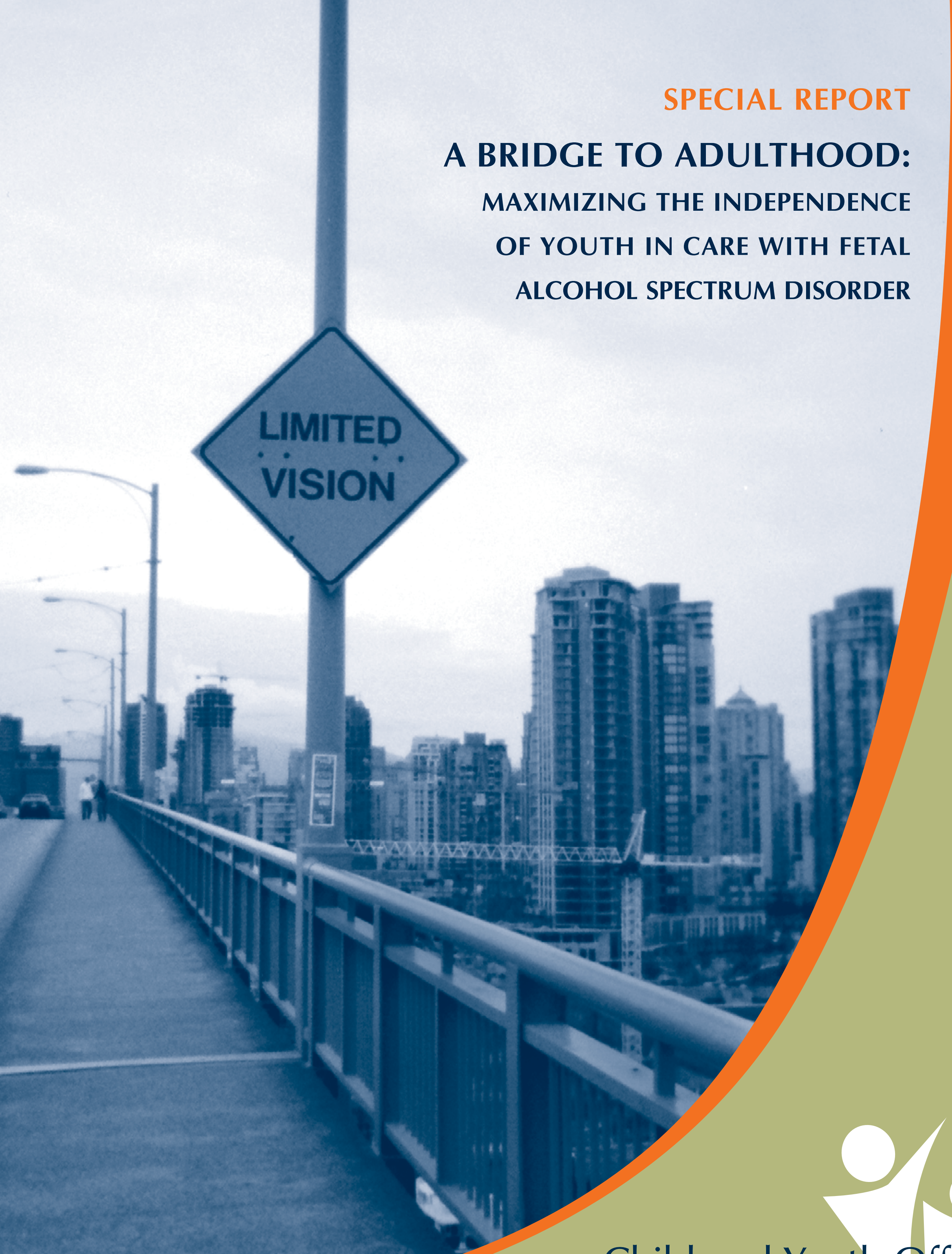
SPECIAL REPORT

A BRIDGE TO ADULTHOOD:

MAXIMIZING THE INDEPENDENCE OF YOUTH IN CARE WITH FETAL ALCOHOL SPECTRUM DISORDER



Child and Youth Officer
for British Columbia

September 2006

Honourable Wally Oppal
Attorney General

As part of my role as Child and Youth Officer for British Columbia and in accordance with the provision of Section 8(3) of the *Office for Children and Youth Act*, I have prepared this special report, entitled *A Bridge to Adulthood: Maximizing the Independence of Youth in Care with Fetal Alcohol Spectrum Disorder*.

This report originated with concerns expressed by Ministry of Children and Family Development staff about the youth in their care with fetal alcohol spectrum disorder (FASD) when they reached age 19 and no longer had the supports the ministry could offer. These concerns led to a joint project looking at the particular needs of these youth and whether and how the system might meet those needs. An advisory committee established as part of the project contributed to the recommendations contained in this special report.

While the focus of this report is primarily on those youth for whom government has responsibility as guardian, their plight is shared by others who are not in government care. The report ends with six recommendations, some of more general application and others dealing specifically with how the government could assist youth in care with FASD in their transition to adulthood.

J Morley

Jane Morley, QC
Child and Youth Officer for British Columbia

Acknowledgments

There are many people I wish to acknowledge for their contributions to the project that gave rise to this special report. First, I would like to thank our partners in the project, the Ministry of Children and Family Development's Vancouver Coastal region, especially Mike White and Sohan Singh, who took a lead in the project on the region's behalf. I want to thank the six youth who were profiled in the project, for letting us look into their lives, as well as their caregivers and social workers, for giving us their time and helping us understand the harsh realities that these youth face. I am grateful to the many members of the advisory committee (listed in Appendix A), not only for sharing their time and expertise, but also for inspiring all of us with their passion. Several others, with whom we consulted during the writing of this report, were also very generous, including Dr. Maureen O'Donnell of Sunny Hill Health Centre for Children, Dr. John Hirdes of interRAI, Jane Cowell of the Ministry of Children and Family Development, and the staff of The Asante Centre for Fetal Alcohol Syndrome. In addition, two practicum students from the University of British Columbia, Autumn Jenkinson and Shelley Hamilton, played a major role in the project and the early stages of preparing the report; Shelley did most of the interviews and continued to work on the project long after her practicum was over.

As ever, I am indebted to the members of my team who worked on both the project and producing this report – in particular my deputy, Fred Milowsky, who had the original idea for the project when he was Interim Chief Executive Officer of the Vancouver Coastal region and led the project when he joined my team.

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Executive Summary

The story this report tells is not a new or surprising one. We want youth in care with fetal alcohol spectrum disorder (FASD) to achieve maximum independence and live full lives in their communities. Yet we are failing to give them a means to do so. We can construct a better bridge for them to adulthood. We should do so, and we should do so now.

This special report is about youth in government care with fetal alcohol spectrum disorder who, when they reach age 19, are not eligible for the adult services provided by Community Living BC and are left on their own to navigate an adult service system not well-suited to their needs.

What we know

Fetal alcohol spectrum disorder is an umbrella term that describes a continuum of conditions that result from prenatal alcohol exposure. FASD is the leading cause of developmental disability among Canadian children, and the most common form of preventable brain damage in the Western world.

Maternal alcohol use during pregnancy can result in physical defects and neurological deficits. These cause complex functional disabilities – often invisible – that affect a person's capacity to function at home, at school or work, and in the community. People with FASD have lifelong difficulties with learning, behaviour and socialization. They often face significant secondary challenges, including mental health problems and substance addictions. And because of the nature of the disabilities associated with FASD, many people with FASD have difficulty living independently without supports and services. They are often at risk of experiencing poverty, homelessness, and trouble with the law.

The critical first step in providing an effective response to FASD is early, accurate diagnosis. Yet getting a diagnosis is often difficult, particularly when maternal alcohol use is not confirmed. Diagnosis requires assessment by a multidisciplinary team, the availability of which is often limited, especially in rural areas.

While diagnosis is important, however, it is only a first step. Assessing the individual's ability to function – at home, at school, and in the community – is also crucial in determining what types of services and supports he or she needs. While there are numerous existing tools for measuring different types of functioning, there is as yet no single comprehensive tool for assessing functioning in individuals with FASD and other functional disabilities. However, an initiative is currently underway in British Columbia to determine the feasibility of developing such a tool.

Youth with FASD do better if they have a structured home environment and an adult, or adults in their lives who advocate for them and help them navigate the system. The types of supports needed by people with FASD vary widely. Getting the supports they need can be particularly challenging because they don't fit into any particular category or program, but may overlap with many.

The project

The transition to adulthood for all adolescents has its challenges. Youth in care face these challenges head on when they turn 19 and the government ceases to be their legal guardian. For youth in care who have FASD, the challenges are even more daunting, in part because their disabilities make it so difficult – often impossible – for them to navigate the adult system.

The Child and Youth Officer for British Columbia and the Ministry of Children and Family Development's Vancouver Coastal region undertook a joint project to look more closely at what could be done to address the concerns expressed by regional staff about youth in care with FASD.

The project looked at six Lower Mainland youth in care with confirmed or suspected FASD. They had a number of things in common. They were all in government care at the time, lived in the Greater Vancouver area, and were within two years of their 19th birthday, at which point they would be expected to live independently. All six youth had confirmed or suspected fetal alcohol spectrum disorder (FASD), which resulted in significant difficulty in functioning, whether at school, at home or in their community. None of the six was street-involved, although some had had brushes with the law and some already had substance abuse issues; all six were amenable to using available services. Finally, because of their disabilities, all six youth were considered to be at very high risk for poverty, homelessness, involvement with the justice system, and other poor outcomes.

Using interviews, questionnaires, and information from caregivers, social workers and the youth themselves, confidential profiles of each youth were created, along with a summary of the types of assistance each would need. These case files were then taken through a simulated review with service gatekeepers to determine what assistance, if any, the youth would qualify for at age 19, as compared to those services and supports which they were judged to be in need of and were currently receiving.

The types of supports identified as required by the youth included:

- supported living services (part-time or full-time caregivers, and supported housing)
- life skills and employment training and assistance
- financial assistance
- mental health and addiction services
- planning and case management services.

The simulation revealed that the adult service system does not offer most of these supports, and those services that are offered are not readily accessible by these youth. For example, although supported living services are offered through Community Living BC, none of the youth (with one possible exception) would be eligible because their IQs are too high, despite the fact that their levels of adaptive functioning are comparable to individuals with much lower IQs. While all of the youth, again with one possible exception, would likely be eligible for Ministry of Employment and Income Assistance disability benefits, the process of applying for and maintaining these benefits would be exceptionally difficult for them without significant, ongoing assistance. BC Housing provides subsidized housing for people with disabilities, but the number of applicants far exceeds the number of available units, and there are very limited options for single people. None of the youth have a formal mental health diagnosis that would make them eligible for mental health services. And for the youth needing addiction treatment, even if they had the capacity to access treatment programs, it is unlikely that treatment based on cognitive approaches would meet their needs, because of their cognitive impairment.

Advice to the provincial government

1. Invest in the development of a tool designed to assess the functional capacities and limitations of individuals requiring government services as an aid to designing appropriate services, and use this functional assessment tool to assist in planning for youth in care with FASD as they transition to adulthood.

2. Expand the eligibility requirements of Community Living BC by recognizing low adaptive functioning as an equally important indicator of the need for lifelong community living services.

3. Develop a cross-ministry plan for youth transitioning to the adult service system, involving in the plan the Ministry of Children and Family Development, the Ministry of Employment and Income Assistance, the Ministry of Health, the regional health authorities, and Community Living BC, and including within the plan:
    - identification of services needed by youth in transition
    - a clear definition of the mandates of each agency to provide those services
    - a strategy to fill any gaps identified
    - strategies to be implemented within the appropriate ministry or agency to make the services offered more responsive to the needs of vulnerable youth, particularly those with FASD and other similar functional disabilities.

4. Provide funding through the appropriate ministry for focused education and training of professionals working with youth with FASD about the implications of this disability for service delivery and their practice.

5. Revitalize the transition planning required by the Ministry of Children and Family Development's service standards, by initially targeting youth in care with FASD or suspected FASD, ensuring that for each youth a planning process is in place that:
    (a) meaningfully engages the youth
    (b) includes adults who are significant in the youth's life in order to encourage the development of a network of support for the youth that will continue past age 19
    (c) incorporates a strengths-based, culturally appropriate approach, and

(d) is informed by:

  - a functional assessment and analysis, based on the use of an appropriate tool and information from those who best know the youth's functioning
  - a diagnostic assessment
  - a social mapping of existing and potential informal adult and community supports
  - if the youth is Aboriginal, a full understanding of the youth's cultural context.

6 Acknowledge the ongoing obligation of government to support youth for whom the government has been guardian, and develop a 19–23 transition-to-adulthood case management program, to be administered by the Ministry of Children and Family Development. Begin by targeting youth in care who have or are suspected of having FASD and who are not eligible for Community Living BC. Include in the program the following features:

- individualized plans designed to maximize independence and smooth the transition to the adult system of supports by age 24
- assignment of a key worker to provide case management services and assist the youth, his or her family and other significant community supports in navigating the adult service delivery system
- graduated levels of support based on an individualized assessment of need and flowing from the individual's transition plan developed in accordance with the Ministry of Children and Family Development's service standards
- a budget to fill gaps in services, to be allocated by the Ministry of Children and Family Development on the basis of relative need
- accessible supported housing options
- direct access to employment training programs delivered through the Ministry of Employment and Income Assistance
- when the youth reaches age 24, a plan that addresses the continuity of services beyond age 24.

About This Report

Most youth aren't expected to leave their family home on their 19th birthday. In fact, census data shows a trend in which young adults are increasingly staying with or returning to their families into their late twenties.

Youth in care, however, usually don't have this option. The government's responsibility for them ends on their 19th birthday, when they are expected to set off to live independently and to function as adults in the world, often with little or no support or assistance from family.

For a particular group of youth in care, this sudden transition to adulthood is particularly difficult. These are youth who have fetal alcohol spectrum disorder (FASD), a largely invisible disability that makes it hard for them to function in the adult world without significant services and support. Because this lifelong disability does not easily fit current eligibility criteria (e.g., it is not a recognized mental health disorder), and may look quite different for each individual, these youth don't qualify for many of the existing adult programs and services they so badly need. And the adult system is not designed to respond to their particular needs and behavioural characteristics. This group is at high risk of experiencing poor outcomes, including poverty, homelessness, and involvement in the criminal justice system – all of which have negative impacts on the health – both general and economic – of our society.

The project

This report grew out of significant concerns expressed to the Child and Youth Officer by staff in the Vancouver Coastal region of the Ministry of Children and Family Development about what happens to youth in their care with FASD who, when they reach age 19, are not eligible for the adult services provided by Community Living BC and are left on their own to navigate an adult service system not well-suited to their needs. We decided to undertake a joint project to look more closely at what could be done to address this concern.

The project involved looking at the plight of six Lower Mainland youth in care with confirmed or suspected FASD who were approaching age 19. The youth selected were not street-involved, and were amenable to using services – in other words, they would be willing to use services if they were available for them and they knew how to access them.

Using interviews, questionnaires, and information from caregivers, social workers and the youth themselves, we created confidential profiles of each youth and a summary of the types of assistance each would need. We then took these case files forward in a simulated review with service gatekeepers to determine what assistance, if any, they would qualify for at age 19, as compared to those services and supports which they were judged to be in need of and were currently receiving. The project is described in more detail in Appendix B, and the specific findings are included in Appendix C.

An advisory committee was established to provide suggestions and guidance in generating any recommendations arising from the project. The membership of the committee, which changed over time, consisted of many skilled and dedicated individuals who serve children and youth in these circumstances, and represented a wide range of provincial government, community, academic, and other non-governmental organizations. A list of the advisory committee members is included in Appendix A.

The special report

A Bridge to Adulthood: Maximizing the Independence of Youth in Care with Fetal Alcohol Spectrum Disorder presents "snapshots" based on the six youth profiled in the project, as a way to illustrate the problems faced by youth in care with invisible, lifelong functional disabilities like FASD as they transition into adulthood.

The report also provides a brief summary of what is known about FASD; the current status of diagnosis and functional assessments; and what is available in the adult service system for young adults who have FASD. It asks two questions: How can we support these youth, particularly those leaving government care, through their transition to the adult service system? And how can we support them in achieving maximum independence and living full lives in their communities?

Finally, the report provides advice for the provincial government. While it focuses on what government should do to support the youth in its care who have FASD as they transition to adulthood, the advice also has implications beyond this group.

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WHO THEY ARE: THE PROFILED YOUTH

The youth who were profiled in the project that gave rise to this report had a number of things in common. They were all in government care at the time, lived in the Greater Vancouver area, and were within two years of their 19th birthday, at which point they would be expected to live independently. All six youth had confirmed or suspected fetal alcohol spectrum disorder (FASD), which resulted in significant difficulty in functioning, whether at school, at home or in their community. None of the six was street-involved, although some had had brushes with the law and some already had substance abuse issues; all six were amenable to using available services. Finally, because of their disabilities, all six youth were considered to be at very high risk for poverty, homelessness, involvement with the justice system, and other poor outcomes.

The youth profiled in the project are similar to many youth, both in and not in care, who have significant difficulty in functioning and a substantive need for services, and who, because of their age, are moving from the child service system to the adult service system.

The following brief "snapshots" are based on the six youth profiled in the project, and are representative of the youth and young adults who are the focus of this report. The names and some other details have been changed in order to protect their privacy.

All six of the youth we interviewed are vibrant human beings, and like all human beings have their strengths and their weaknesses, their aspirations and their limitations. The profiles include an assessment of the youth's ability to function in the adult world from the perspectives of both the youth and their caregivers and social workers. The youth's self-assessments tend to be more optimistic than the assessments of the caregivers and social workers. The particular cognitive dysfunctions associated with FASD (e.g., problems with judgment, a poor capacity for abstraction, and problems with social perceptions) may be one of the reasons for this discrepancy. Any suggestion that the youth are unrealistic in their positive sense of their future is not intended to be disrespectful. In fact, the sense of hope and aspiration expressed by these youth is a strength that will help them in their transition to adulthood.

IQ ranges

An intelligence quotient or IQ is a score derived from a set of standardized tests of intelligence. IQ scores between 90 and 109 are considered to be "average"; 80–89 is "low average"; 70–79 is "borderline"; and below 70 is "extremely low."

Dan

- **Diagnoses:** neo-natal abstinence syndrome, probable fetal alcohol syndrome, attention deficit disorder (ADD), severe expressive/receptive language disorder
- **IQ:** 87 (low average)*
- **Other characteristics:** difficulty with critical thinking; poor impulse control; difficulty regulating emotions; at risk for inappropriate sexual behaviours

Dan is 18. He has lived in his current foster home since he was 18 months old. His five siblings have also been or are currently in care.

Dan has a speech impediment that, combined with his very soft voice, makes it hard to understand what he is saying. He has difficulty understanding boundaries, and tends to invade other people's physical space; as a result, he has been charged with uttering threats, as well as with breaking and entering. Because of his difficulty regulating emotions, he can become suicidal when distressed; he has tried to commit suicide by cutting his wrists and by injecting gasoline into his veins, and therefore requires close supervision to protect him from harming himself.

In four months, Dan will turn 19, and will have to leave government care. He doesn't have a clear idea about what this will mean for him. He thinks it would be "cool" if he could continue to live in his foster home, but is vague about any other living arrangements, and says he hasn't thought about it yet. He also hasn't thought about what he will do when he leaves school. He isn't really interested in thinking about the future.

When Dan gets money, he spends it all. He doesn't know how to shop for groceries, pay bills or make change. He doesn't know how to make a doctor's appointment. When asked if he knows how to cook, he says he knows how to make hotdogs and Kraft dinner in the microwave.

When asked if he is ready to go out on his own, Dan says "not yet." When asked what he needs to learn before he will be ready, he says he needs to learn "how to cook spaghetti and meatballs."

Dan's caregiver and social worker express great concern about his ability to look after himself once he turns 19. It is unlikely that Dan will be able to get any significant support from his family. The social worker says Dan will need ongoing support and assistance in most areas, including housing, educational/vocational training, personal care management, financial matters, management of medications, and mental health.

*Despite Dan's higher IQ scores, a psychiatrist at the Child Adolescent Psychiatric Unit at B.C. Children's Hospital told Dan's social worker that his disabilities and needs are not unlike those of a youth who would have an IQ score of 50 (considered as mild to moderate mental retardation).

Carla

- **Diagnoses:** suspected FASD; significant learning disabilities, including dyslexia
- **IQ:** 80–89 (low average)
- **Other characteristics:** self-destructive behaviours, often threatening suicide; verbal aggressiveness that often alienates her from her peers; substance abuse

Carla is almost 18. She came into foster care when she was eight years old, after it was discovered that she was single-handedly taking care of her mother, who was ill and had psychiatric problems. Since then, Carla has lived in many different foster homes, with many of her placements breaking down. She has no siblings, and the only other relative she knows about lives in another province and has very limited contact with her.

Carla currently attends an alternative school, where she can get a lot of extra help. She has few friends. She is increasingly using alcohol and marijuana, which she doesn't see as a problem.

In just over a year, Carla will turn 19 and have to leave government care. With no family to turn to, she will be on her own. Carla laughs about this, and says she doesn't care. But she admits that she will need some help: "Cause I'll be just like now. I'll have to find a place, and then get a good job. It would be nice to have help for a while because you have to get used to having to work all of the time and making money and it would be nice to have some help with rent and food and stuff."

Both Carla's caregiver and her social worker agree that while she will probably be able to look after her personal hygiene and nutrition needs, she will likely need support in other areas, including financial assistance and support for educational or vocational training and finding and keeping employment. She might also need help from mental health services for her anger problems, substance abuse and self-destructive behaviours.

Jamie

- **Diagnoses:** fetal alcohol syndrome (FAS)
- **IQ:** 81 (low average)
- **Other characteristics:** difficulty understanding abstract concepts; difficulty with impulse control; poor judgment; substance abuse issues

Jamie is 18. An Aboriginal youth with a friendly, quiet manner, he speaks in short, simple sentences. He came into government care as a young child, and has had many placements since then. His current placement is a specialized foster home in which he has his own living quarters but can have meals with and receive support from his foster family. He likes this arrangement.

Jamie currently attends an alternative school, where he receives extra individual attention. He tends to gravitate to the Downtown Eastside, where his friends are involved in illegal activities such as drug trafficking, and he is easily taken advantage of.

In about six months, Jamie will be 19, and will no longer be in government care. He expects to get an apartment and a job, and doesn't anticipate having any problems doing so, although he doesn't know how he will go about it or what type of job he will try to get. He believes he will be able to take care of himself – cooking nutritious meals, paying bills, and making and keeping medical and dental appointments. He's not particularly worried about any of this, as he feels his family and friends will help him out.

However, Jamie's caregiver and social worker both express great concern about all of these areas. While he may be able to manage his personal care to some extent, they feel that he will not be able to find and keep an apartment, manage his money, look after his health and get the help he needs in the community without significant support. The social worker believes Jamie will need ongoing contact with a case worker, as well as financial assistance, help finding and keeping employment, and drug and alcohol counselling.

Melanie

- **Diagnoses:** alcohol-related neurodevelopmental disorder (ARND)
- **IQ:** 72 (borderline)
- **Other characteristics:** substance abuse; tendency to become violent

A vibrant 17-year-old Aboriginal youth from the Shuswap territory, Melanie has goals and aspirations that include opening her own beauty salon. She has been in care for most of her life, because of her mother's inability to look after her as a result of a number of factors, including alcohol misuse, spousal abuse, and other related inter-generational effects of the residential school system. Melanie lived in 31 placements between infancy and age 13. She currently has many questions about why her biological family is the way it is.

Melanie has had extensive involvement with the youth criminal justice system, and has been in and out of custody several times since she was 13. Most of the charges have been related to violent offences, all which have taken place while Melanie was under the influence of drugs or alcohol.

Melanie uses or takes part in a number of services and programs at a local youth resource centre, including the youth advisory council, a girls group, and the health clinic. She has also been seeing the youth addictions counsellor at the centre – sporadically but over the course of several years. The consistency of Melanie's contact with staff at the centre is seen to have been extremely beneficial for her. In addition, the Aboriginal cultural teachings and practices that Melanie has experienced through some of the programs at the centre have had a positive effect, providing her with culturally appropriate life skills.

Melanie says that she only found out about her diagnosis from her lawyer during a recent court appearance. She doesn't fully understand what it means, beyond the fact that her mom drank while she was pregnant. She also believes that she has a drinking problem herself; she really wants to quit but can't.

Although she believes she will be able to live on her own when she turns 19, Melanie recognizes that she will need help. Both her caregiver and her social worker believe that Melanie needs extensive help – currently and on an ongoing basis when she turns 19. They mentioned numerous supports that Melanie will need, including a full- or part-time caregiver, regular caseworker contact, financial assistance, mental health services, drug and alcohol counselling, educational and vocational training support, and assistance in finding and keeping employment.

Ashley

- **Diagnoses:** fetal alcohol syndrome (FAS); sensory integration disorder; fetal Dilantin syndrome; attention deficit disorder; significant learning disabilities
- **IQ:** 83 (low average)
- **Other characteristics:** high anxiety; extremely low self-esteem

Ashley is an articulate 17-year-old who has been in care since she was 11. Before coming into care, she lived with a number of relatives, who were unable to manage her behaviours. Ashley's mother couldn't look after her children because of serious substance abuse problems and a deteriorating medical condition.

Although she projects a certain confidence when she speaks, Ashley's caregiver says that she is often excessively anxious. She has a history of bladder incontinence (which her caregiver attributes to her high anxiety level) – although this problem has resolved itself since Ashley's current placement began four years ago.

Ashley needs close supervision in all of her activities. She is not able to manage money, buy groceries, or take public transit independently. However, she attends high school full-time, where she takes courses she enjoys and is successful in; the focus is on developing job-readiness skills. She works in the school cafeteria, where she is given simple tasks and receives the supervision she needs.

Ashley repeatedly mentions how happy she is in her current placement, where her foster parents know how to support people with FASD. She also talks about how "terrible" her previous placement was, because her caregivers did not treat her well, and continually blamed her for her behaviours – including chronic forgetfulness – which she later learned were a result of FAS. Ashley says it was really helpful for her to finally be diagnosed, and to understand that the FAS was responsible for her memory and sensory problems. Learning about FAS, together with the support of her foster parents, helped her stop blaming herself. She also enjoys talking to people and telling them what it is like to have FAS.

Ashley appears to have a realistic understanding of what living independently involves. She will be able to stay at her current placement when she turns 19; she'd like to stay until she is at least 25, and maybe longer. She doesn't think she'll be ready to be on her own for a long time. She recognizes that she is unable to do a lot of things, like paying bills, cooking meals, doing laundry, and arranging for medical appointments, but she expects to improve her skills in these areas over the next few years. She would like to work in the food industry, and intends to take a college course that is specifically designed to assist people with learning disabilities in finding employment.

Ashley's caregiver describes her as a wonderful person who is exceptionally hard on herself, frequently apologizing for things that require no apology. Her extreme need to please also makes her vulnerable to abuse. A lot of work has been done in the foster home to increase her self-esteem and confidence.

While Ashley talks very well, her actual understanding of what she hears and reads is quite limited; she doesn't retain a lot of learning, and is simply not aware of her effect on others. She continually makes mistakes that, combined with her auditory processing slowness, cause her a lot of social anguish. The caregiver notes that Ashley has no friends at school, with the exception of one person who takes advantage of her.

Both the caregiver and social worker agree that Ashley is very dependent on others for support, and will need constant, ongoing assistance for the rest of her life, especially because of her memory and sensory problems. Without daily positive support, the caregiver believes Ashley would deteriorate very quickly, and the skills she is working so hard to develop would disappear.

Lanny

- **Diagnoses:** fetal alcohol syndrome (FAS); attention deficit hyperactivity disorder (ADHD), and severe learning disabilities.
- **IQ:** 76 (borderline)
- **Other characteristics:** severe problems with both long-term and short-term memory; poor judgment; lack of sense of boundaries; life-threatening food allergies

Seventeen-year-old Lanny has lived in his current placement for seven years. With the exception of younger siblings who also have special needs and are in ministry care, he has no living family. His only parent died on the street.

Because his teachers find his behaviours too disruptive in the classroom, Lanny attends school half time: although his manner is quiet and serious, he can't remember what he is supposed to be doing, so he continually asks questions. Lanny is functionally illiterate, functioning at a low primary grade at school; he knows how to print his name, but can't write it. Because of his low level of literacy, he is permitted to take non-academic courses only.

Lanny appears to have to concentrate very intently in order to understand what is being said. He can respond only to the most simple and concrete questions. However, he is able to say that he will not be ready to go out on his own when he turns 19. He seems to be aware that he needs the support provided by his current foster home. He also says that he will be going to college to take a job preparation course for people with disabilities. He's not sure what kind of job he would like to get, but he likes videos and pets.

Lanny's caregiver describes him as totally dependent on others for all aspects of his care, requiring constant supervision. He is unable to prepare simple meals, do laundry, count change or manage medical appointments. Because of his sensory and memory problems, Lanny is usually not aware when he is ill, or even when he is hungry; without constant reminders, he would not remember to eat or look after any of his other personal care needs. With no sense of time, he also needs to be reminded of each of his daily routines.

Lanny's memory impairment is so severe that he basically functions without memory. He copes by making things up – which results in people who don't understand his disability accusing him of deliberately lying – or by continually asking for information. Lacking a sense of boundaries, he often says inappropriate things to people. He is easily frustrated and overwhelmed, and needs a calm and supportive environment.

Both the caregiver and the social worker agree that Lanny will always require a very high level of support in all areas in order for him to remain safe. Both emphasize their concerns about his extreme dependency and vulnerability. The social worker predicts that without this level of support, Lanny will easily be taken advantage of because he has little or no judgment about dangerous situations. His health and abilities could also deteriorate in the future, and he may require an even greater level of support as he ages. It is unlikely that Lanny will ever be able to live independently, and he will always need to live with a caregiver.

Lanny has no family members who can look after him when he turns 19. His foster family has said that Lanny can continue to live with them once he leaves ministry care, as there is no possibility that he can live without this support.

What is fetal alcohol spectrum disorder (FASD)?

Fetal alcohol spectrum disorder (FASD) is an umbrella term that describes a continuum of conditions that result from prenatal alcohol exposure. *FASD is not a diagnostic term.* The specific conditions or diagnoses within the spectrum include:

- **Fetal alcohol syndrome (FAS) with confirmed maternal alcohol exposure** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure, (b) the presence of all three characteristic facial features (short palpebral fissures, smooth philtrum, and thin upper lip), (c) growth deficiency, and (d) evidence of impairment in at least three central nervous system (brain) domains.
- **FAS without confirmed maternal alcohol exposure** – Diagnostic criteria are the same as above, but prenatal alcohol exposure is unconfirmed.
- **Partial fetal alcohol syndrome (pFAS)** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure, (b) the presence of two of the characteristic facial features, and (c) evidence of impairment in at least three central nervous system (brain) domains.
- **Alcohol-related neurodevelopmental disorder (ARND)** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure and (b) evidence of impairment in at least three central nervous system (brain) domains.
- **Alcohol-related birth defects (ARBD)** – a range of congenital anomalies, including malformation and dysplasia. ARBD is not an umbrella term or diagnostic term, and should be used with caution.

Diagnosis is achieved through a formal multidisciplinary diagnostic process.

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WHAT WE KNOW

Fetal alcohol syndrome (FAS) was first identified in 1973, and provided a diagnostic label for the variety of characteristics caused by prenatal exposure to alcohol. With the terminology and understanding of the condition evolving since that time, the term *fetal alcohol spectrum disorder* (FASD) is now used to describe the range of diagnoses that result from prenatal alcohol exposure, including FAS, partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

FASD is not a diagnosis in itself, but an umbrella term used to describe the full range of alcohol-related effects.

Incidence rates in B.C.

FASD is the leading cause of developmental disability among Canadian children, and the most common form of preventable brain damage in the Western world.

Overall incidence rates of FASD in British Columbia are not definitively known. Current estimates of the prevalence of FASD among newborns range from a low of three to a high of nine out of every 1,000 births per year. But FASD advocates suggest that these numbers are likely significantly lower than the actual reality, because of the under-reporting and under-diagnosing of FASD.

It is difficult to determine the incidence and prevalence of FASD because of inconsistent criteria for diagnosis, poor access to diagnosis, the invisible nature of the disability in many cases, and the increasing challenge of diagnosis as a child or youth matures. For children and youth who are in foster care or adopted, diagnosis can be even more difficult, because of a lack of information about prenatal alcohol exposure.

With further refinement of the diagnostic criteria and procedures for FASD and increased awareness and knowledge among health professionals, it may be possible to get better data on the incidence and prevalence of FASD.

Effects of prenatal alcohol exposure

Maternal alcohol use during pregnancy can result in both physical defects and neurological deficits.

Physical defects resulting from prenatal alcohol exposure can include:

- growth retardation (both prenatal and post-natal)
- distinctive facial features
- decreased head size
- central nervous system dysfunction
- malformations of the heart, kidneys, bones, or vision and hearing systems
- dental abnormalities
- immune system dysfunction.

Prenatal damage to the brain can result in neurological deficits, including:

- problems with memory, attention and judgment
- poor capacity for abstraction
- poor impulse control
- problems with social perception
- higher-level receptive and expressive language deficits
- low IQ, learning disabilities and cognitive difficulties
- higher-than-normal pain tolerance
- epilepsy
- impairment of fine motor skills
- difficulty coordinating gait and hand–eye functions.

The combination of these characteristics is different for each individual. Many people with FASD have none of the visible physical characteristics associated with FASD, or they may have some of the physical characteristics at a younger age but grow out of them as they mature; as a result, FASD is most often an invisible disability. Additionally, some people with FASD have only a few of the neurological deficits, while others have more of them, or a greater degree of severity.

The range of severity in the impact of maternal alcohol use is related to a number of factors. These include the timing, frequency and quantity of alcohol use, as well as a variety of contextual, individual and genetic factors that interact with alcohol use and result in the specific impact on the fetus. Research has shown that certain brain regions are more susceptible to the impacts of alcohol than others; research has also suggested that maternal binge drinking is the pattern that holds the most risk for the fetus.

FASD is often invisible: in the majority of cases, affected individuals have neurological damage without exhibiting any physical abnormalities, or they grow out of the physical characteristics as they mature, but the cognitive and behavioural problems continue. The lack of physical abnormalities does not necessarily mean that the disability is any less severe.

However, regardless of the unique individual experiences of FASD, in all cases where FASD is present, irreversible brain damage has occurred, resulting in lifelong difficulties with learning, behaviour and socialization.

Secondary disabilities

Without appropriate supports and services, individuals with FASD (and other functional disabilities) are at risk of developing secondary disabilities – disabilities that are not inherent in the individual at birth, but evolve in response to the primary disabilities as the person matures. For example, people with FASD may perform poorly in school as a result of learning difficulties that are not well understood or responded to within the educational system; this in turn can result in marginalization during formative years, and disrupted school experiences, as well as lifelong struggles related to low educational achievement.

In a study of 415 youth and adults from the Seattle cohort*, Streissguth, Barr, Kogan, and Bookstein (1996, as cited in Clark, 2003) reported that individuals with FASD experience such difficulties as:

- mental health problems (more than 90%)
- disrupted school experience (60%)
- trouble with the law (60%)
- confinement for mental health, drug and alcohol, or criminal issues (50%)
- inappropriate sexual behavior (50%)
- alcohol and drug problems (30%)
- problems with employment (79% of 90 individuals)
- dependent living (83% of 90 individuals), and
- problems with parenting (57% of 30 individuals who were parents).

***The Seattle Longitudinal Study on Alcohol and Pregnancy**

Literature on adults with FASD is sparse. Most of the existing literature has come from the Seattle Longitudinal Study on Alcohol and Pregnancy, commonly known as "the Seattle cohort," at the University of Washington. This major study, which has been underway for more than 30 years, has focused on a single sample of more than 400 children born in Seattle, beginning with interviews with the mothers before birth, followed by eight examinations during childhood and further interviews in adulthood.

FASD and mental health problems

The Seattle cohort research has shown that more than 90% of adults with FASD experience mental health problems. This is supported by research on adults with FASD in British Columbia by Erica Clark (2003), who found that 92% of the 62 participants in her study had at least one mental health diagnosis. The primary diagnoses were depression, attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), and panic disorder.

Clark also notes the significant difference between the rate of mental health diagnoses among adults with FASD and the rate for the intellectually disabled population, which is 30–40% (Percy & Brown, 1999, as cited in Clark, 2003).

Identifying FASD

The critical first step in providing an effective response to FASD is early, accurate diagnosis. When people who have FASD and other functional disabilities are not diagnosed, or are inaccurately diagnosed with another condition, the resources and interventions provided for them are often ineffective.

Getting a diagnosis is often difficult, and made more difficult if maternal alcohol use is not confirmed. Diagnosis requires assessment by a multidisciplinary team that typically consists of a pediatrician, a speech and language pathologist, a registered psychologist, and an occupational therapist; a psychiatrist may also be part of the team. The availability of these teams in British Columbia is limited, especially for those living in rural areas.

Recent diagnostic developments may increase the accuracy and consistency of diagnoses and of incidence rates, in addition to enhancing the response to the needs of people with FASD. In May 2005, the Canadian Diagnostic Standards formally established the diagnostic criteria for the range of diagnoses included under FASD. In addition, researchers at Toronto's Hospital for Sick Children have developed a test that involves analyzing a newborn's first bowel movement to identify prenatal alcohol exposure; while this test would serve only as one diagnostic tool among several, it could enhance the ability of medical professionals, multidisciplinary teams and families to identify potential problems in development and to refer children for early assessment and diagnosis.

The Asante Centre for Fetal Alcohol Syndrome

The Asante Centre for Fetal Alcohol Syndrome, in Maple Ridge, B.C., provides a range of services for children, youth and adults affected by FASD, based on a family-centred, multidisciplinary approach. Services include diagnosis and assessment, outreach to remote communities, coordinated care planning, counselling, speech and language therapy, support groups, consultation services, and training. Staff include a physician/pediatrician, registered psychologist, speech and language pathologist, and family nurse clinician.

Sunny Hill Health Centre for Children

Sunny Hill Health Centre for Children, part of Children's and Women's Health Centre of British Columbia, offers specialized services to children and youth (from birth to 19) with disabilities, their families and communities throughout the province. Services include assessment, diagnosis, consultation, referral, and, in select cases, treatment. Sunny Hill also provides services in the areas of development and behaviour for children and youth with complex disabilities, such as those acquired as a result of prenatal exposure to alcohol or other drugs.

Assessing the ability to function

While diagnosis is important, it is only a first step. The next step is to assess the individual's ability to function – at home, at school, and in the community – in order to determine what types of services and supports he or she needs.

There are numerous existing tools for measuring different types of functioning. However, there is as yet no single comprehensive tool for assessing functioning in individuals with FASD and other functional disabilities. Developing a functional assessment tool for children and youth is especially challenging, because it has to take into account the fact that children and youth develop over time (i.e., one child's functioning at age two will look different from the same child at age five, and age 10, and so on) – and not all in the same way.

In British Columbia, the Ministries of Children and Family Development, Education, and Health are currently involved in a cross-ministry initiative aimed at developing a functional assessment tool. Phase 1 of the project has involved a feasibility study by interRAI, an international collective of researchers who have participated in the development of a set of functional assessment tools in various areas (e.g., geriatrics, developmental disabilities). The study is addressing the question of whether it is possible to develop a functional assessment tool that will effectively cover the broad range of developmental ages and stages of childhood and adolescence.

Another related initiative in British Columbia is the establishment of a provincial network for the screening and assessment of complex developmental behavioural conditions. The term *complex developmental behavioural conditions* does not identify a separate diagnostic group, but encompasses a broad range of conditions. The program will offer assessment services for children and youth who have significant difficulties in multiple areas of function, with or without a known or suspected history of exposure to a substance with neurodevelopmental effects.

Unfortunately, these initiatives will be too late to help the youth profiled in this report and many similar youth in care who are already in their mid-teens; however, the early diagnosis and functional assessment that will be available within the next few years should help others who are currently younger.

Five domains of function

The World Health Organization recently developed the International Classification of Functioning, Disability and Health (ICF). Rather than simply classifying disabilities by traditional labels, it looks at the individual's functioning in five domains:

- body functions – physiological functions of body systems, including psychological functions
- body structures – anatomical parts of the body, such as organs and limbs and their components
- activity – execution of a task or action
- participation – involvement in a life situation
- environmental factors – the physical, social and attitudinal environment in which people live and conduct their lives.

Effective responses

The risks associated with FASD are reduced if the strengths of individuals who have these disabilities are recognized and honoured by those around them. People with FASD are like everyone else in needing supportive environments that help them build on their strengths in order to address their personal challenges.

During this project, caregivers, social workers and various professionals provided anecdotal reports of people with FASD doing well when they found themselves in the right environment. These stories all shared two common characteristics. First, the person had been provided with a structured home environment in which he or she is nurtured, strengths are acknowledged and promoted, the characteristics of the disability are understood, and strategies to assist the person in mediating them are explored and implemented. Second, someone – whether a family member, adopted family member, and/or volunteer – had taken on the informal role of one-on-one worker or advocate, helping the person navigate the service delivery system to access the services he or she needs but may be unable to access independently.

Supported housing

Supported housing gives adults with FASD the core of the structure they require to cope effectively as adults in the community. Supported housing – which includes a wide range of options, from semi-independent living to fully staffed facilities – provides structured environments, ongoing social support, and in some cases close supervision, all of which have been identified as effective interventions for adults with FASD.

Case management

Because of the problems with impulsiveness and memory that characterize FASD, many young adults with FASD lack decision-making and critical thinking skills, and have difficulty making and/or following through on plans for their daily living and future prospects. Case management services address this issue.

Case management was developed in the 1970s as a way of delivering services to people with severe functional disorders. There are a variety of case management approaches with different levels of intervention. All involve some form of outreach and assessment, service planning, linking of the client with necessary services, monitoring of the client's situation, and advocacy support.

An approach with a high level of intervention is Assertive Community Treatment (ACT), which involves an interdisciplinary team that provides direct treatment and services using more

Adaptive skills versus IQ

People with FASD and other functional disabilities often do not qualify for services for people with intellectual disabilities, because their IQs are too high. Yet their adaptive functioning might be similar to that of an individual with a much lower IQ.

Adaptive functioning refers to the capacity of children, as they develop, to adapt in an age-appropriate way to the demands of their environment. While there is a very wide range of normal development, children typically follow a relatively predictable course of development as they grow. This is true for the acquisition of adaptive functioning skills as well.

The components of adaptive functioning identified by the American Psychiatric Association and the American Association on Mental Retardation are communication, self-care, home living, social, community use, self-direction, health and safety, academics, leisure, and work.

Research has shown that problems with adaptive functioning skills in people with FASD can actually increase over time (Institute of Medicine, 1996, as cited in Clark, 2003). One study of adults with FASD found that the mean IQ for participants with FAS was 79; however, 83% of the participants were unable to live independently because of significant deficits in their adaptive functioning (Streissguth, Barr, Kogan, & Bookstein, 1996, as cited in Clark, 2003).

aggressive outreach and engagement techniques. Research has shown the ACT approach to be an effective community-based service delivery model for people with severe mental illness, preventing both homelessness and repeated hospital admissions and institutionalization. (Morse, 1999; Government of British Columbia, 2002)

Culturally appropriate services

Currently, more than half of youth who age out of government care at 19 are Aboriginal. A significant number of those youth will have FASD, whether diagnosed or not. We know that Aboriginal youth respond best to services that strengthen their ties to their culture and their communities. Young Aboriginal adults with FASD have been found to respond well to services that are culturally appropriate, that are provided by Aboriginal people, and that connect the youth with their community.

In addition, the Aboriginal cultural teachings and practices that **Melanie** has experienced through some of the programs at the centre have had a positive effect, providing her with culturally appropriate life skills.

3

TRANSITIONING TO THE ADULT SERVICE SYSTEM

All adolescents have to make the transition to adulthood, and for all of them this stage in life has its challenges. For youth in care, the expectation of becoming fully adult is thrust upon them on their 19th birthday, when, regardless of their capacity to meet the challenges of transitioning to adulthood, the government ceases to be their legal guardian. For youth in care who have FASD, the challenges are even more daunting, in part because their disabilities make it so difficult – often impossible – for them to navigate the adult system.

The types of supports that were identified by the caregivers and social workers as required for the youth we profiled included:

- supported living services (part-time or full-time caregivers, and supported housing)
- life skills and employment training and assistance
- financial assistance
- mental health and addiction services
- planning and case management services.

For youth with FASD who have not been in care, their families often provide some or all of these supports for years after the youth reaches 19, and advocate for them to receive services they need in the adult system. However, youth in care with FASD rarely have families available to assist them in adulthood or advocate on their behalf within the adult system. Up to age 19, they live in homes with caregivers who support them in their day-to-day living, and social workers who provide case management services and connect them to needed services. When these youth reach 19, they are on their own.

A recent study in British Columbia found that only 13% of adults with FASD were capable of living independently (Clark, 2003).

We discovered in the simulation phase of the project that the adult service system does not offer most of the supports identified as needed by the youth we profiled, and those services that are offered are not readily accessible by these youth.

To the extent that the identified supports and services are offered by government in the adult system, they are for the most part accessed through Community Living BC, the Ministry of Employment and

Income Assistance, and the Ministry of Health. What follows is a brief consideration of what is offered by these government agencies, and what that means specifically for the youth we have profiled in this report and more generally for all youth in care with FASD.

Community Living BC

Community Living BC provides many adult services and supports identified as needed by the youth we have profiled, notably supported living services, life skills and employment training and assistance, and planning services.

CLBC is a provincial Crown agency created to assist individuals (children and adults) with developmental disabilities "to achieve maximum independence and to live full lives in their communities." It does this by providing and funding community support services for individuals with developmental disabilities and their families, and by encouraging shared responsibility and building on the capacity of the individuals' families and communities to support the individual living in the community.

Supported living services

Every one of the caregivers of the youth we profiled identified the ongoing need for some level of living support (full-time or part-time caregiver or supported housing services) for these youth after they reached 19.

Community Living BC is the only government agency that offers or funds full-time or part-time caregiver services or supported housing for adults, with the exception of adults who suffer from severe dysfunction as a result of mental illness, in which case the Ministry of Health offers these services as an alternative to institutionalization.

> Because of his sensory and memory problems, **Lanny** is usually not aware when he is ill, or even when he is hungry; without constant reminders, he would not remember to eat or look after any of his other personal care needs.

Planning and case management services

Planning and case management services were identified as key for the youth we profiled. Like many young adults with FASD, they lack decision-making and critical thinking skills, making planning for their daily living and future prospects very difficult. Also, their memory problems make it difficult for them to remember appointments and follow through with plans.

Jamie expects to get an apartment and a job when he turns 19, although he doesn't know how he will go about it or what type of job he will try to get. The social worker believes Jamie will need ongoing contact with a case worker.

Again, with the exception of adults with severe dysfunction connected with mental disorders who are living in the community, the adult system does not offer these planning and case management–type services except through Community Living BC.

Community Living BC plays an important role in facilitating individualized planning for adults with developmental disabilities and in coordinating community living support provided by Community Living BC with services provided by government and community resources. The approach taken by Community Living BC is strongly oriented to family involvement in planning and case management. It does not see its role as providing "case management services" directly, but rather as supporting family and community members in providing these services.

Youth with FASD who reach 19 in care often don't have the family supports that Community Living BC assumes in its model. Also, their tendency to poor impulse control and problems with social perception often alienate adults and create obstacles for them in developing an adult support network. The model of depending on family and community involvement in planning and case management will not necessarily work with these youth.

Carla came into foster care when she was eight years old. Since then, Carla has lived in many different foster homes, with many of her placements breaking down. She has no siblings, and the only other relative she knows about lives in another province and has very limited contact with her.

Eligibility for Community Living BC

Currently, to be eligible for Community Living BC services past age 19, an individual must be diagnosed by a registered psychologist as having the developmental disability of mental retardation, based on the diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV).[1] One of the criteria for mental retardation is a "measured intellectual functioning of below 70–75."

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[1] The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, commonly known as the DSM-IV, is the main diagnostic reference of mental health professionals in Canada and the United States.

A recent British Columbia Supreme Court case – *Fahlman v. CLBC and* others, BCSC 900 Date: 20060612 – successfully challenged the application of the IQ eligibility criteria to exclude from Community Living BC a young adult with autism and FASD, whose IQ was higher than 70 but whose adaptive functioning was very low. That decision is under appeal at the time of the writing of this report.

Of the youth profiled in this report, only Melanie (whose IQ, at 72, is within the standard error range) might be eligible for Community Living BC under its current eligibility criteria, and then only if she receives a diagnosis of mental retardation from a registered psychologist. Melanie had not as yet received that diagnosis. None of the rest of the youth would qualify, because their IQs are low average or borderline, and are therefore too high for a diagnosis of mental retardation: Dan (87), Carla (low average), Jamie (81), Ashley (83) and Lanny (76).

Despite **Dan's** higher IQ scores, a psychiatrist at the Child Adolescent Psychiatric Unit at B.C. Children's Hospital told Dan's social worker that his disabilities and needs are not unlike those of a youth who would have an IQ score of 50 (considered as mild to moderate mental retardation).

Ministry of Employment and Income Assistance

The Ministry of Employment and Income Assistance offers some of the services identified as necessary for the youth we profiled, primarily income assistance and some (to date minimal) employment and life skill supports for people with disabilities.

The initial eligibility of the youth we profiled for these services is not clear, and the youth's capacity to maintain eligibility is a concern. The relevance and adequacy of the employment and life skills services to youth with FASD is questionable.

Eligibility for disability benefits

Individuals with a confirmed diagnosis within the FASD continuum may apply for disability benefits. A diagnosis of learning disabilities is not in itself sufficient, even if FASD is suspected. In addition to obtaining an FASD continuum diagnosis, the applicant must also establish that his or her condition will significantly affect daily functioning, and necessitate some level of care both at present and in the future.

With the possible exception of Carla, who has suspected FASD, all the youth we profiled have a diagnosis within the FASD continuum. All of them have a sufficiently low level of functioning to qualify them for disability benefits. The issue for them is whether they will be able to establish their disability through the Ministry of Employment and Income Assistance application process.

The process for applying for benefits is quite onerous and the forms are challenging to fill out. One of them must be signed by a physician. Someone with FASD would require considerable support to organize and carry through with the application process.

For a youth in care, this means support from the social worker. There are varying levels of awareness among social workers about FASD, and without a specialized understanding, it is easy for them to assume that the behaviour of youth with FASD is "acting out behaviour" rather than a manifestation of a lifelong disability. For this reason, FASD often goes undetected among youth in care, and social workers do not recognize a responsibility for assisting the youth on their caseload in applying for disability benefits.

Maintaining benefits

Even if the youth is assisted by his or her social worker in the initial application process, he or she may fail to meet the administrative requirements to maintain the benefits. There is an annual form to be filled out and a meeting with a Ministry of Employment and Income Assistance worker to be attended. The types of problems that are characteristic of people with FASD, in particular poor memory, lead to lack of follow-through with administrative requirements and missed appointments.

The workers who administer disability benefits are often unfamiliar with FASD and the implications of the disability for their clients. As a result, they may have unrealistic expectations of the abilities of the young person or react to his or her behaviours, not understanding them to be connected to the disability, which can increase the risk of the youth not being able to maintain their eligibility for benefits.

Financial assistance and money management

The primary benefit offered by the Ministry of Employment and Income Assistance to people with disabilities is income assistance.*

Receiving income assistance does not guarantee being able to manage the money received. Difficulty managing money was mentioned often as an issue for the youth we profiled.

Service providers told us that there are no life skills training programs available from or funded by government for youth like Jamie and the

***Subsidized housing**

In addition to the financial assistance provided by the Ministry of Employment and Income Assistance, subsidized housing is provided for people with disabilities by BC Housing. However, the number of applicants for BC Housing currently far exceeds the number of available units. BC Housing also has very limited options for single people (i.e., as opposed to families).

People are contacted when their case comes up for consideration. This presents a problem for transient people whose contact information may be changeable.

When the profiles of Dan, Carla, Jamie, Melanie and Ashley were presented to BC Housing, the same response was received: "No housing available at present. Impossible to determine ranking in terms of need without an actual application."

others profiled, except through Community Living BC. The Ministry of Employment and Income Assistance announced in June 2006 the allocation of $7.5 million to help individuals "develop their basic life skills, enhance their quality of life, and prepare them to participate more fully in their community."

When **Dan** gets money, he spends it all. He doesn't know how to shop for groceries, pay bills or make change. When asked if he knows how to cook, he says he knows how to make hotdogs and Kraft dinner in the microwave. When asked if he is ready to go out on his own, Dan says "not yet." When asked what he needs to learn before he will be ready, he says he needs to learn "how to cook spaghetti and meatballs."

Employment supports

In addition to income assistance, the Ministry of Employment and Income Assistance offers employment supports to help people on income assistance get work. For the most part, these supports are targeted to those who are more employable than youth with FASD tend to be. Individuals who are eligible for disability benefits are not expected to work. If they can work and want to, there are incentives and specialized services to help them take advantage of employment opportunities. Pursuing these limited opportunities requires a degree of initiative that may be difficult or impossible for young people with FASD to achieve.

Melanie has goals and aspirations that include opening her own beauty salon. Her caregiver and social worker mentioned numerous supports that she will need, including educational and vocational training support, and assistance in finding and keeping employment.

The employment services that the Ministry of Employment and Income Assistance provide (e.g., courses in interview preparation and computer skills) require cognitive abilities that youth with FASD often do not have.

Carla is a good example of the difficulties a young adult with functional disabilities will face in accessing employment supports. Because she has only suspected FASD and no confirmed diagnosis other than learning disabilities, and she appears to be able to manage her daily living, she may not qualify for disability benefits. She will then be expected to be employed. Her caregiver and social worker agree that she will need help finding and keeping employment. However, her learning disabilities will make it difficult for her to take advantage of the employment services the Ministry of Employment and Income Assistance provides.

The Ministry of Health

Several of the youth we profiled were identified as having incipient mental health and/or addiction issues, and their social workers and caregivers identified mental health and addiction services as services they will likely require in adulthood.

The Ministry of Health offers mental health and addiction services through its five regional authorities and its hospitals. However, unless their conditions deteriorate and become severe, the likelihood is that the youth we profiled will not access these services. Even if they were to access them, the treatments provided are not designed for people with the particular neurological dysfunctions common to those with FASD.

Mental health services

There are generally three ways to access adult mental health services:

- directly, by calling or going to a community mental health centre or clinic
- by referral from a doctor, or
- through an emergency psychiatric admission to hospital.

Community mental health centres

Community mental health centres usually provide office-based services and have an intake process that requires at least one initial interview, often by telephone, followed by a waiting period of at least one week before the person is seen by a mental health practitioner. There are sometimes wait-lists that are managed through a triage system to ensure that people with the highest need are seen first.

Young people generally have difficulty accessing these office-based services without some advocacy and structure provided by experienced adults who care about them. Youth with FASD have a particular need for someone to help them work their way through the intake process and to make sure they make appointments. For youth with FASD who have been in care and are therefore unlikely to have adult supports, the process of getting on the wait-list and attending office-based appointments often presents an insurmountable barrier to these services.

Referrals from physicians

Specialized community mental health services can only be accessed by referral from a physician. These services include inpatient and outpatient psychiatry, neuropsychiatry, and some community-based outreach services, such as Fraser Health's Assertive Community Management Team, for people with serious mental disorders and functional disabilities. A clear mental health diagnosis is a requirement for such referrals, and if mental health problems are not seen as the primary diagnosis this requirement is not met. Often, mental health problems experienced by people with FASD are not seen by their physicians as their primary diagnosis, and FASD is not itself included in the DSM-IV as a recognized mental health condition.

The fact that FASD is not in the DSM-IV has contributed to the invisibility of FASD in the mental health field. In Erica Clark's study of the experiences of 62 adults with FASD in British Columbia, many of the caregivers who participated in the study reported a lack of support for and understanding of FASD, particularly among mental health professionals.

Emergency psychiatric admission to hospital

Although **Dan** can become suicidal when distressed and has tried to commit suicide by cutting his wrists and by injecting gasoline into his veins, he is likely to access mental health services only if he ends up in a hospital Emergency ward.

Because FASD is not a primary mental health diagnosis, even though approximately 90% of people with FASD will have mental health problems, they are likely to receive adult mental health services only if they experience a mental health crisis or psychiatric emergency for which they can be admitted to hospital.

Someone experiencing a mental health crisis is usually admitted either for a few hours in Emergency or a few days in a short-term psychiatric unit. Once the person is stabilized, he or she may be referred to a specialized service or program, or to a community mental health centre, for monitoring or ongoing treatment. Again, for the young person with FASD and no adult supports, carrying through with the community care services is an enormous challenge.

Treatments

The most common treatments for mental health problems are drugs and cognitive therapies. Drug therapies work only if the drug is taken consistently. The memory problems of people with FASD make this difficult. Cognitive therapies, which involve reflection on and awareness of one's own thoughts, are not effective for people with FASD because of their cognitive disabilities.

Addiction services

Drug and alcohol counselling services, which are the most common type of addiction services, are generally accessed in the same way as community mental health services, with the same challenges for youth with FASD who do not have adult supports. In some areas, drug and alcohol counselling services are integrated with mental health services and are accessible through community mental health centres. However, more often than not, the services are provided through separate programs and in different locations. This increases the access barriers for young people with low levels of adaptive functioning.

Drug detoxification and rehabilitation programs are generally accessible through mental health and drug and alcohol counselling services or by referral from a doctor or psychiatrist. There are usually wait-lists for non-private detoxification and rehabilitation programs.

Generally, access to addiction services involves significant wait-lists, and unless the youth is involved in the criminal justice system, access is unlikely. Without referrals as a result of involvement with the criminal justice system, a person has to want to access addiction services. Both access and the therapies recommended involve a level of self-recognition and awareness that is often not present in young people with FASD.

Carla has significant learning disabilities. She currently attends an alternative school, where she can get a lot of extra help. She has few friends. She is increasingly using alcohol and marijuana, which she doesn't see as a problem.

When we looked for drug and alcohol treatment services for the youth profiled, we found that there were no services specifically designed for youth and adults with FASD. Carla, Jamie and Melanie all appear to have a present or looming serious substance abuse problem. None of them are likely to access adult addiction services.


LIMITED
VISION

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REFLECTIONS AND ADVICE

The story that this report tells is not a new or surprising one – at least not for those who work with vulnerable young people transitioning to adulthood. They know that too often we are collectively failing these young people who require the support of the system outside their families if they are going to achieve maximum independence and live full lives in their community.

One of the enduring memories for me in this project will be the passion exhibited in the advisory committee meetings. The membership of this committee changed over time but each time the group gathered I observed a shared frustration with the state of services for these young people, and almost a desperation for something to be done. Participants all had first-hand experience of youth with significant functional disabilities being left to fend for themselves, obviously without the tools to manage on their own. The pleasure and relief of those who participated in the advisory committee meetings at connecting with others with similar experiences and concern was one of the positive outcomes of the project.

When I first suggested doing a special report on this issue, I expected the reaction to be one of cynicism – no more reports, action is what is needed. Contrary to my expectations, the enthusiasm for the idea was inspiring: anything to shed some public light on the issue.

The reaction when I told others throughout the province about this project was two-fold. They unanimously supported the idea of highlighting the issue of service gaps for youth transitioning to adulthood. At the same time, from many I received a "yes-but" response – the "but" being that it is not only youth in care in the Vancouver Coastal region with FASD who face the issue of gaps and inaccessibility when they transition to the adult system. Other youth are not getting the support they need in the adult system either: youth in care with FASD in other regions, youth with FASD whether they are in care or not, youth with functional disabilities other than FASD, youth in care who do not have a diagnosable functional disability but whose adult support network effectively ends at age 19, and so on.

Despite the temptation to broaden the project, in the end we decided to continue to highlight youth in care with FASD, realizing that what we have to say about them will have wider application. Besides, there are reasons for government to focus on youth in care with FASD. They are less likely to have family supports, and, as their guardian, the government has an obvious special responsibility for them. Also, we can speak with authority about the effects of FASD because something is known about it; and we should speak loudly about what we know because what is known is not known widely. Even those who work in the various aspects of the system with which youth with FASD do or should come into contact have limited awareness of the effects of FASD. FASD, like many functional disabilities, is invisible; it has a lifelong effect. By putting a spotlight on youth in care with FASD, issues facing a large number of youth beyond this group are brought into sharp relief.

Having said that, I want to sound a cautionary note about the focus on FASD. Tying eligibility for government programs to labels – especially labels that have significant social stigma attached to them – is fraught with risk: assumptions are made that should not be made; the idea that the real promise for the youth lies in a recognition of the youth's strengths may get lost; and instead of developing programs and policies that provide opportunities for independence, continuing dependence may be encouraged.

In the course of working on this project, I heard a number of solutions proposed. One was to create a separate government agency specializing in fetal alcohol spectrum disorder, its prevention, identification and treatment – an FASD BC. The creation of such an agency would indeed recognize the uniqueness of FASD, its prevalence and the severity of the problems caused by it across the entire span of human life. Yet there is a problem with this solution. It perpetuates an approach – using diagnosis as a gateway to services – that is a feature of our current system and that we should be rethinking, not replicating. The gateway approach leads to an undue emphasis being placed on getting a certain diagnosis in order to meet the criteria to gain access to services, rather than on assessing and responding to individual needs, whatever the diagnosis. It leads to jurisdictional disputes that result in the very gaps in services that exist for the youth we profiled in our project. Furthermore, it is not ultimately sustainable in public policy terms to create separate authorities for each disability that for whatever reason happens to gain the attention of the public or the courts.

There is no single FASD solution. In fact, the wide range of conditions within the FASD continuum brings home the need for an individualized approach to services. Somehow, however the government chooses to divide up administrative responsibilities for services, we need to figure out how to design those services in a way that is responsive to the individual needs of the child, youth or adult in question, and that takes into account the context of their families, communities and culture.

What follows is advice to the provincial government on how to address gaps in and inaccessibility to services for vulnerable youth in care with FASD, by taking a more individualized approach to designing services. Some of the advice has general application; other advice focuses solely on the group highlighted in this report – youth in care with confirmed or suspected FASD.

I believe that by applying an individualized approach to this target group, who so obviously need support and services at age 19, the general value of the approach will increasingly be recognized. Demonstrated success in responding to the needs of youth in care with FASD will persuade policy-makers to take a more individualized approach with all youth who require ongoing support and services past age 19, whether in care or not, and whether diagnosed with FASD or not.

Advice to the provincial government

A functional assessment tool

Recommendation 1: Invest in the development of a tool designed to assess the functional capacities and limitations of individuals requiring government services as an aid to designing appropriate services, and use this functional assessment tool to assist in planning for youth in care with FASD as they transition to adulthood.

Diagnosis is important because it helps us to know what we are dealing with, and what are the reasonable expectations and particular needs of the individual who requires support. Diagnosis should not, however, be the gateway to government services. The work currently being done and referred to in this report on developing a cross-ministry functional assessment tool is promising. Focusing more on functional assessment in designing appropriate services makes sense. It supports the goal of maximizing independence by shedding light on the obstacles that the individual faces in functioning independently. It gets away from labeling and encourages practical problem-solving designed for the individual. Investment in developing a tool will pay dividends, because it will allow for the planning of services that are more effective in meeting individual needs.

Expanded eligibility for Community Living BC

Recommendation 2: Expand the eligibility requirements of Community Living BC by recognizing low adaptive functioning as an equally important indicator of the need for lifelong community living services.

Community Living BC is the one existing government agency that assumes responsibility for certain individuals who require lifelong government-funded supports. It also has embraced an individualized approach that designs a service plan to maximize independence, taking into account the individual's family and community context. It is well-suited to provide the supported living services identified as required by the young people profiled in our project.

Supports and services provided by Community Living BC should be available to adults with severe functional disabilities, regardless of their IQ. It simply doesn't make sense that Dan, who has been assessed by a psychiatrist as having disabilities similar to youth who would test in the 50 IQ range, should not be eligible for lifelong support services because his IQ is 87, or that Lanny (IQ of 76), who because of his sensory and memory problems needs constant reminders to eat and to look after any of his other personal care needs, should similarly be denied eligibility.

A cross-ministry plan for youth transitioning to the adult service system

Recommendation 3: Develop a cross-ministry plan for youth transitioning to the adult service system, involving in the plan the Ministry of Children and Family Development, the Ministry of Employment and Income Assistance, the Ministry of Health, the regional health authorities, and Community Living BC, and including within the plan:

- identification of services needed by youth in transition
- a clear definition of the mandates of each agency to provide those services
- a strategy to fill any gaps identified
- strategies to be implemented within the appropriate ministry or agency to make the services offered more responsive to the needs of vulnerable youth, particularly those with FASD and other similar functional disabilities.

Lack of clarity of the mandates of the various ministries and agencies with responsibility for social services for adults is one of the frustrations faced by those involved in planning for a youth who has been receiving services and is about to turn 19. Often the answer from the ministry or agency is, "We are not responsible. Try them." Too often, at the end of the day there is no "them" to turn to. A gap – more like a gaping hole – exists for this youth.

To overcome this jurisdictional response, a cross-ministry plan is needed that will identify the typical service needs of youth with FASD and similar functional disabilities, clarify mandates and develop strategies to fill the identified gaps.

To the extent that there are adult services available, we know from what we have learned in our other work that the adult system is not designed to be accessible to youth generally. The particular cognitive and behavioural dysfunctions of youth with FASD exacerbate these accessibility issues. The adult system should be made to work for them. Without an expectation being set for each ministry and agency responsible to develop strategies for change, these issues will persist. These expectations could be set in the context of a cross-ministry plan for youth transitioning to the adult service system.

Education of professionals

Recommendation 4: Provide funding through the appropriate ministry for focused education and training of professionals working with youth with FASD about the implications of this disability for service delivery and their practice.

While much is known about FASD, it is not known widely. Increasing awareness among professionals who deal with youth with FASD is crucial because of the prevalence and invisibility of the condition, and the likelihood of misunderstanding and mismanaging the behaviours of young adults with FASD.

Regardless of whether youth with FASD come under the umbrella of Community Living BC, they will need to access the existing adult system of services. For the adult system to be responsive to the particular needs of young people with FASD, the professionals within the various aspects of the adult service system must understand the impacts of FASD on the individuals they serve and the implications of these impacts on service delivery and practice.

Transition planning for youth in care with FASD

Recommendation 5: Revitalize the transition planning required by the Ministry of Children and Family Development's service standards, by initially targeting youth in care with FASD or suspected FASD, ensuring that for each youth a planning process is in place that:

(a) meaningfully engages the youth

(b) includes adults who are significant in the youth's life in order to encourage the development of a network of support for the youth that will continue past age 19

(c) incorporates a strengths-based, culturally appropriate approach, and

(d) is informed by:

- ia functional assessment and analysis, based on the use of an appropriate tool and information from those who best know the youth's functioning
- a diagnostic assessment
- a social mapping of existing and potential informal adult and community supports
- if the youth is Aboriginal, a full understanding of the youth's cultural context.

Parents plan for their children's transition to adulthood. Recognizing this, the Ministry of Children and Family Development has a standard that requires transition planning for all children in continuing care.

It may seem odd to make a recommendation to the Ministry of Children and Family Development to follow its own policy and standards, and it is beyond the scope of this report to make any definitive statement about whether, or the extent to which, the transition plan standard is already being followed. However, with respect to youth in care with FASD, we do know that there is room for improvement, or at least a reason to breathe some life into the standard. (As an aside, I would observe that while the idea of transition planning is a good one, for those with the responsibility for applying the standard, putting energy into it may seem pointless if there are no resources with which to plan.)

> Before a youth leaves care because he or she is reaching the age of majority, assist him or her in:
>
> - finding an appropriate place to live
> - obtaining basic living essentials
> - obtaining adequate financial and social support
> - obtaining information about health care coverage, therapeutic support and emergency assistance when necessary
> - securing funding for post-secondary education or training
> - identifying or maintaining relationships with family members, natural helpers, informal and formal supports, cultural community and other significant people, and
> - if the youth has a trust fund, obtaining information about the fund from the Public Guardian and Trustee.
>
> – from Children in Care Standard 16: Promoting Resiliency and Skills for Successful Community Living

The advice here is to take a target group that is clearly going to require adult services, without which it is likely to be a financial burden on other aspects of the system. The economic good sense of an approach that maximizes independence is obvious, and makes it easier to persuade those with government fiscal responsibility to allocate resources to target this group and implement well-thought-out plans. If some measurable positive outcomes are identified, and these outcomes are realized and demonstrated, the evidence will be there to persuade policy decision-makers to expand this approach and allocate resources to it.

Any parent who has tried to plan for his or her child's future knows that engagement of the youth in the planning process is crucial. Unless the youth "owns" the plan, the likelihood of success is low. This is as true with youth with FASD as it is with any youth. So it is extremely important to meaningfully engage the youth in the planning process.

The resources available to meet a youth's needs increase if more adults, not just family members but also interested community members, are involved in the planning. Bringing community members into planning for these youth could be a very concrete way for the Ministry of Children and Family Development to pursue its plan to engage more with community in its work.

A network of supportive adults will also increase the chances of a successful transition to adulthood.

A sense of belonging is a factor in protecting the youth from the risks of succumbing to the pressures of the adult world. With Aboriginal children in particular, the sense of belonging is increased if they are given opportunities to connect to their culture and their communities. It is also important to build on the strengths of the youth, rather than focusing solely on managing his or her weaknesses.

Finally, a good plan is based on good information, which is why a diagnosis and a functional assessment are important.

A transition-to-adulthood case management program

Recommendation 6: Acknowledge the ongoing obligation of government to support youth for whom the government has been guardian, and develop a 19–23 transition-to-adulthood case management program, to be administered by the Ministry of Children and Family Development. Begin by targeting youth in care who have or are suspected of having FASD and who are not eligible for Community Living BC. Include in the program the following features:

- individualized plans designed to maximize independence and smooth the transition to the adult system of supports by age 24
- assignment of a key worker to provide case management services and assist the youth, his or her family and other significant community supports in navigating the adult service delivery system
- graduated levels of support based on an individualized assessment of need and flowing from the individual's transition plan developed in accordance with the Ministry of Children and Family Development's service standards
- a budget to fill gaps in services, to be allocated by the Ministry of Children and Family Development on the basis of relative need
- accessible supported housing options
- direct access to employment training programs delivered through the Ministry of Employment and Income Assistance
- when the youth reaches age 24, a plan that addresses the continuity of services beyond age 24.

We all know that the state of adulthood does not magically arrive on a child's 19th birthday (except according to the law). Some aspects of adulthood come earlier. Increasingly, complete independence from families is not achieved by young people until they are into their late twenties. It is time that we stopped pretending otherwise when it comes to youth in government care. Post-majority support should be available for all youth in care, but it is absolutely crucial for youth with FASD.

Integrated case management has worked for children and youth in care with complex needs. Adult case management services have proven to be a successful approach for adults with significant and disabling mental health problems, allowing them to function in the community, instead of being institutionalized. We know that people with FASD have particular difficulties planning, managing and advocating for themselves, and that the obstacles to adult services are such that planning, navigating complex systems and advocating in the face of scarce resources is exactly what is needed for a successful transition to the adult service system.

When ministries and agencies turn away individual youth who are in need of continuing services when they reach 19, they are motivated in part by understandable budget concerns. They all have enormous responsibilities and limited funds to fulfill those responsibilities. In an environment of limited budgets, the ministry or agency wants to avoid setting a precedent by acknowledging responsibility that could have the effect of opening up the floodgates and creating a demand that could not be met within the resources allocated to that ministry or agency. Yet from an overall government perspective, the youth in care with FASD who experiences significant functional disabilities obviously should be receiving the services that are sought.

Despite a general acknowledgment about how important it is to provide these young people with services, nothing will happen to fill this gap until there is both an identified responsibility and a budget to make it happen.

Of course, age 24 is no more magical than age 19. However, five more years of government taking some level of responsibility for the youth in its care is a good start. Furthermore, the concept of the Ministry of Children and Family Development continuing to have responsibility for youth to age 24 is reflected in section 12.3 of the *Child, Family and Community Service Act*, which allows the Ministry of Children and Family Development to have agreements with former youth in care to provide support and financial assistance.

Agreements with young adults

12.3 (1) Subject to the regulations, a director may make a written agreement with a person who, until the person's 19th birthday,

  (a) received support services or financial assistance, or both, under section 12.2,
  (b) was in the continuing custody of a director or the permanent custody of the Superintendent of Family and Child Service, or
  (c) was in the guardianship of a director of adoption or of a director under section 29 (3) of the *Family Relations Act*.

(2) The agreement may provide for support services or financial assistance, or both, to assist the person while

  (a) enrolled in an educational or vocational training program, or
  (b) taking part in a rehabilitative program.

(3) The agreement may be renewed or, after an interval, another agreement under this section may be made, but, whether one or more agreements are made,

  (a) the total of the terms of all agreements with all directors, and all renewals to all agreements, relating to the same person must not exceed 24 months, and
  (b) no agreement may extend beyond the person's 24th birthday.

– Child, Family and Community Service Act

Conclusion

The image on the cover of this report – the Burrard Street bridge to downtown Vancouver, the big city in the background, and the sign "limited vision" – will conjure up different thoughts for each of us as we consider its relevance to the messages in the report. For me, I see the big city on the other side of the bridge as representative of adulthood – filled with opportunities and dangers.

A bridge is a man-made structure. The one on the cover is designed to facilitate access to the city. As a society, we have a responsibility to build a bridge to facilitate access to adulthood for the youth in government care who have FASD and cannot be expected to manage the transition to adulthood on their own.

The "limited vision" sign could be a reminder of the disabilities of young people with FASD, or of the invisibility of those disabilities. I prefer to think of it as a statement that so far we have been too limited in our vision for these youth. We want them to partake of the opportunities of adulthood, to be full participants in our society. Yet we are failing to give them the means to do that.

We can construct a better bridge. We should do so, and we should do so now.

Glossary

adaptive functioning: refers to the capacity of children, as they develop, to adapt in an age-appropriate way to the demands of their environment. The components of adaptive functioning identified by the American Psychiatric Association and the American Association on Mental Retardation are communication, self-care, home living, social, community use, self-direction, health and safety, academics, leisure, and work.

alcohol-related birth defects (ARBD): a range of congenital anomalies, including malformation and dysplasia. ARBD is not an umbrella term or diagnostic term, and should be used with caution.

fetal alcohol effect (FAE): a term formerly used to describe people who had been exposed to alcohol prenatally and exhibited manifestations consistent with FAS except for the facial characteristics, or when the impairment was not sufficient to satisfy the criteria for a full FAS diagnosis. *This term is no longer used.*

fetal alcohol spectrum disorder (FASD): an umbrella term that describes a continuum of conditions that result from prenatal alcohol exposure. *FASD is not a diagnostic term.* The specific diagnoses within the spectrum include:

- **fetal alcohol syndrome (FAS) with confirmed maternal alcohol exposure** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure, (b) the presence of all three characteristic facial features (short palpebral fissures, smooth philtrum, and thin upper lip), (c) growth deficiency, and (d) evidence of impairment in at least three central nervous system (brain) domains.
- **FAS without confirmed maternal alcohol exposure** – Diagnostic criteria are the same as above, but prenatal alcohol exposure is unconfirmed.
- **partial fetal alcohol syndrome (pFAS)** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure, (b) the presence of two of the characteristic facial features, and (c) evidence of impairment in at least three central nervous system (brain) domains.
- **alcohol-related neurodevelopmental disorder (ARND)** – Diagnostic criteria include (a) confirmed prenatal alcohol exposure and (b) evidence of impairment in at least three central nervous system (brain) domains.

Diagnosis is achieved through a formal multidisciplinary diagnostic process.

fetal Dilantin syndrome: a range of congenital anomalies, including minor face and limb birth defects, growth problems and developmental delay, resulting from fetal exposure to the anticonvulsant drug Dilantin.

functional assessment: assessment of an individual's ability to function – at home, at school, and in the community – in order to determine what types or services and supports he or she needs. While there are numerous existing tools for measuring different types of functioning, there is as yet no single comprehensive tool for assessing functioning in individuals with FASD and other functional disabilities.

neonatal abstinence syndrome: a constellation of signs and symptoms exhibited by infants born with drug dependencies because of the mother's substance abuse during pregnancy.

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Appendix A: The Advisory Committee

Membership on the advisory committee was quite fluid. The following individuals participated at some point during or throughout the life of the committee:

The Asante Centre for Fetal Alcohol Syndrome	Tina Antrobus Dr. Kwadwo Ohene Asante Audrey Salahub
B.C. Federation of Foster Parent Associations	Sheila Durnford
Canada Northwest FASD Research Network	Jan Lutke
FASD Support Network of B.C.	Sandi Berg Donna Wheway
Federation of B.C. Youth in Care Networks	Teresa Lum
Fraser Health Authority	Tina Donnelly Amtul Humayun
Ministry of Children and Family Development, Provincial Services	Jane Holland
Ministry of Children and Family Development, Vancouver Coastal	Andrea Clarke R. J. Evans Doug Portfors Jennifer Semenoff Sohan Singh Mike White Sharon White
Ministry of Human Resources	Sharon Belli
Pacific Community Resources Society	Ruth Annis Kristine Kredba
PLEA Community Services Society of B.C.	Tim Agg
South Vancouver Youth Centre	Sebastian Martin
Squamish Elder/Leader	Robert Nahanee
Sunny Hill Health Centre for Children	Norma Carey
University of British Columbia	Shelley Hamilton Richard Sullivan Richard Vedan

Urban Native Youth Association	Horace Fox
Vancouver Coastal Health	Lynda Campbell Ruth Hess-Dolgin Lorna Howes Deborah Simpson
Vancouver Police Department	John DeHaas
Vancouver Aboriginal Child and Family Service Society (Guardianship)	Wally Rupert
Youth Transition Conferencing	Gaye Smith

Appendix B: The Project

The project addressed two fundamental questions:

- What gaps in services, if any, are likely to affect youth with confirmed or suspected FASD as they age out of MCFD care?
- What recommendations for systemic change, if any, are warranted arising from this project?

To answer these questions we conducted case studies of six youth in care with suspected or confirmed FASD. We developed a questionnaire for the youth, their caregivers, and their social workers to determine the current and projected needs of each youth. From the information generated by the questionnaires, we created a case profile for each youth. These case profiles were then taken forward to a simulated interview to assess the services each youth would qualify for upon leaving the child care system.

The youth

Through discussions with care providers in the Ministry of Children and Family Development's Vancouver Coastal region, we identified six youth – three males and three females – who appeared likely to experience problems with services, because, although they had confirmed or suspected FASD, they did not appear to meet eligibility criteria for continuing adult services.

The six youth:

- were aged 17 or 18 at the time
- were in ministry care under a continuing care order
- had an accessible social history on file
- had IQ scores above 70, making them ineligible for adult community living services once they turned 19
- had no strong family or social ties to rely on once they turned 19 and left care
- had a diagnosis of confirmed FASD or suspected FASD
- regardless of the status of their FASD diagnosis, had high special needs as a result of severe learning disabilities, poor social and adaptive skills, problems with language processing, and/or mental health problems
- were identified by social workers and/or caregivers as needing ongoing support once leaving care due to high special needs.
- were in stable placements and were willing to accept support
- were able to participate in an interview (i.e., had adequate verbal language skills).

Informed consent was obtained from caregivers to include the youth in the project.

The questionnaire

In order to create the profiles for each youth, we developed a questionnaire for the primary caregiver of each youth and the social worker closest to each individual case. This orally administered questionnaire provided an opportunity for the caregivers to describe the services they believe the youth will require beyond age 18.

The questionnaire, which we termed a measure of perceived autonomy, contained 32 scaled questions about the perceived current care needs and the projected future care needs of the youth in care. Areas covered included:

- personal hygiene
- ability to manage needed medications
- ability to manage financial matters (e.g., to pay bills, manage money, etc.)
- ability to meet personal nutrition needs
- ability to judge/know when he or she has needs
- ability to identify and contact needed help in the community
- ability to and understanding of how to maintain family contacts
- ability to make needed appointments
- ability (memory, cognitive ability and motivation) to *keep* these appointments
- ability to introspect and identify personal needs
- ability to find suitable housing
- skills needed to retain this housing

- judgment and intuition needed to avoid being taken advantage of
- ability to practice the impulse control needed to avoid social, economic or legal problems
- availability of family, friends or others who are committed to assisting him or her over the long term
- projected ability to function independently at age 19.

Each question had five response options, scored as follows:

Response	**Score**
Never	0
Sometimes	1
Most of the time	2
Almost always	3
Don't know	0.5*

* A response of "don't know" was scored as 0.5 in value because in all cases, interviewees indicated that by saying "I don't know," they meant "never or almost never" but were hesitant to use the absolute "never" response.

Scores were averaged. An average score of less than 1 was judged to indicate an acute need for support, 1 to 2 indicated significant need for support, and 2 to 3 indicated that the youth is fairly capable of autonomy in the areas measured.

In addition, caregivers and social workers indicated, from a list of possible supports and services, those supports and services that he or she felt the youth would actually qualify for when the youth transitioned out of care at age 19.

Interviews were also conducted with the youth, where feasible. These were less formal, open-ended discussions about how the youth felt he or she was doing, and what help the youth felt he or she would need in the future.

The case profiles

Information from the questionnaires and information was combined with known existing case information, to create a case profile for each youth. Every effort was made to keep the identities opaque to those reading them. The profile provided a summary that could be used in a simulation exercise to determine what (if any) gaps really will be likely as the youth reaches age 19.

The simulation exercise

After review and approval of an interim project report by the advisory committee, a simulation exercise was conducted with service gatekeepers and providers to determine what (if any) post-majority services would likely be accessible by the youth.

The individual case profiles were presented to gatekeepers responsible for the following four areas, all of which were indicated in the questionnaire and interview results as required for these youth:

- social assistance – Ministry of Employment and Income Assistance
- housing – BC Housing
- living assistance – Community Living BC
- mental health – members of Vancouver Coastal Health mental health services transition committee.

The core question asked of the gatekeeper for each case was, "Given the case profile, would the individual qualify for service?"

In addition, all of the profiles indicated a present or future need for addiction services. Research was conducted to ascertain what services would be available and accessible to these youth.

Limitations

Self-report data create certain limitations to the findings of any study, because they are based on subjective observations and perceptions of experience. However, the profiles show that in most cases, assessments of the youth have been conducted outside this study. Taken together, we believe the findings of this project accurately reflect the real situations of the six youth.

Appendix C: Project Findings

The caregiver and social worker questionnaires contained 32 scaled questions about the perceived current care needs and the projected future care needs of the youth in care. Each question had five response options, scored from 0 to 3. The responses to each question were then averaged, and each youth had two average scores: one from the caregiver and one from the social worker. An average score of less than 1 was judged to indicate an acute need for support, 1 to 2 indicated significant need for support, and 2 to 3 indicated that the youth is fairly capable of autonomy in the areas measured.

The average scores for each of the youth, for their estimated current and future levels of autonomy, are shown below.

Youth	**Caregiver**		**Social worker**	
	Current	Future	Current	Future
Ashley	0.87	0.53	0.77	0.50
Carla	1.96	2.26	1.73	1.97
Dan	1.87	1.77	0.84	0.65
Jamie	–	–	1.09	1.15
Lanny	0.20	0.29	0.29	0
Melanie	–	–	–	–

– = survey was not completed

How to Reach Us

By phone

In Victoria call 356-0831
Elsewhere in B.C. call
toll-free 1-800-476-3933

By email

cyo@gov.bc.ca

By fax

Victoria: 250-356-0837
Vancouver: 604-775-3205

By mail

PO Box 9207 Stn Prov Govt
Victoria BC V8W 9J1

At our offices

Vancouver
901–808 West Hastings Street
Victoria
4th Floor, 1019 Wharf Street

www.gov.bc.ca/cyo

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Child and Youth Officer
for British Columbia

QP #4500146421