



# Young Adult Transition from High School to Adult Life

An Exploration of Family Member and Self Advocate Experiences

## A Plain Language Report

Community Living Research Project

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This review was prepared by the *Community Living Research Project* based at the School of Social Work, University of British Columbia. This document is part of a larger research project exploring the Community Living supports and services available locally, provincially, nationally, and internationally for adults with developmental disabilities.

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## Reading this report

This paper is a plain language report adapted from a full academic/government report called "Young Adult Transition from High School to Adult Life: An Exploration of Family Member and Self Advocate Experiences" produced by the Community Living Research Project.

To help people read this plain language report some words and phrases have been defined. Definitions are in brackets (example) and follow the word or phrase. Some words and phrases are underlined with a star at the end of the word (for example – definitions\*). Words that are underlined can also be found in the "Glossary" at the end of the report. There are some quotes from people who took part in this research. These quotes are in boxes throughout the report. Please note that in this report, "adult" refers to adults with developmental disabilities. If you need more help reading this paper, please ask a friend.

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## Introduction

In the spring and summer of 2006, the Community Living Research Project held group interviews with 35 adults (Self Advocates) and 70 family members throughout the province of British Columbia. Interviews were held in:

- the Lower Mainland,
- the Interior,
- Vancouver Island,
- the North, and
- Powell River.

The research also involved phone interviews with family members who lived in remote\* (far off places) areas of the province. The goal of the interviews was to get feedback from people with disabilities and their families about programs and services for adults.

Participants were asked to share their experiences with community living supports in four topic areas. Those areas were

- (1) Young adults leaving high school and going into adulthood,
- (2) Residential options\* (i.e. living arrangements),
- (3) Non-residential supports\* (e.g. day programs, work), and
- (4) Services for seniors.

Interviews were recorded, typed, and looked at using computer software. The results of the study are organized in this report by topic area in the following way:

- A. What is working? What is helpful?**
- B. What is not working? What is unhelpful?**
- C. Barriers (things that get in the way)**
- D. Gaps**
- E. Desires/Aspirations (hopes and dreams)**

This report only summarizes (goes over) what family members and young adults said about their experience of the high school transition (leaving high school for adult life).

### **Young Adult Transition**

"Transition", for the purposes of the Community Living Research Project, means the move from high school to adult life that happens for young people between the ages of 18-24. As young people get ready to leave high school, they have new parts of their lives to think about. This time of transition (change) includes life changes and new experiences as these individuals move from school to independent living and working.<sup>1</sup> The transition from school requires all students to participate in some preparation. For students with a disability, this preparation may be a bigger process. Ideally, planning will focus on the strengths, abilities, and interests of the young person.

Transition can be a complicated (hard) and frustrating process as individuals and families try to understand and seek support from a new service system.

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<sup>1</sup> (Wehman, 2001)

Other research found that young people with developmental disabilities say the following are important parts of their lives:

- Getting a job,
- Spending time with friends and family,
- Having "adult" status (for example, having a space or place of their own), and
- Self-determination\* (independence and making one's own decisions).<sup>2</sup>

The supports most frequently needed, asked for, and received for young adults has included:

- Help in getting/receiving community service (e.g. day programs or day support),
- Help in finding and keeping a job, and
- Help in organizing and receiving public or private transportation.<sup>3</sup>

#### **A. What is working? What is helpful/useful?**

Family members were asked to talk about what was helpful during their experience of the transition process. However, much of the stories family members shared about the high school transition were about those things that were not helpful. This means that there is not a lot of information included in this section.

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<sup>2</sup> (Cooney, 2002)

<sup>3</sup> (Johnson et al., 1997)

## Transition supports

Some family members talked about supports they made use of during transition that were helpful. Examples of these helpful supports included:

- Participating in a transition group for young adults and parents,
- Taking an extra year of school to allow for better planning or an opportunity for the young person to mature (grow up), and
- Organizing services so that they some old services continue while some new ones start rather than having all services end at once.

The transition group was a place for parents to meet up and talk about transition related issues and get support from one another. The young adult part of the group allowed young people to meet up with friends and build relationships. An extra year of school allowed some young adults to move slowly into life after high school. The extra year made it possible for young people to stay connected to and get support from the school system. However, some parents worried that some transition supports were keeping their child occupied (busy) and were not providing any real benefits (good things).

## Creative options

Some parents worked with service providers (agencies) to get creative about how a young person leaving high school can be supported. The family member often had to be persistent (determined) in order to work in this way with agencies. One parent said,

*"...he's not the kind of person who easily fits into a hole of any shape. He needs to create his own. So, just having somebody there who was really good at planning...(who) would sit down with us with information at different times along the way, to help us grow and lean into it and send us in direction."*

Another family with a transitioning young adult made an individualized (unique to the person) support option by starting a business for their child based on his interests.

### **B. What is not working? What is unhelpful?**

Family members were asked to talk about hard parts of their experience of the transition process. Family members used the following words to describe their experience of transition:

- "Very scary"
- Feelings of "powerlessness"
- "Bumpy transition"
- "Everything stops"
- "It's too much all at once."

### **Things are always changing – nothing stays the same**

One thing that got in the way of planning for young people was the fact that social workers or facilitators kept changing. Family members talked about their confusion and frustration around support worker changes. For some people, having different support workers meant that transition planning was usually done by a support worker who did not really know the young person. One parent said, *"...there was a specific meeting for her. It was okay, but my concern there is that the social workers have changed so frequently (often) that they didn't really know her and you're doing a meeting about her future."*

In British Columbia, when a young person with a developmental disability turns 19, they must switch from child to adult services. This change can be difficult because people have to learn about a new support system. It is also difficult because



young people have to meet new support people and leave old support people behind. This can be disruptive (upsetting) and confusing.

Some parents talked about a time of limbo (in between two things) when their child was about to turn 19. Young adults would get a new social worker for adults when they moved into the adult system. But the social worker for children would start to close the young adult's file before they had an adult social worker or facilitator. This meant that sometimes young adults did not have a social worker. This was very confusing for families because they had to figure out this transition on their own.

### **Different support systems do not know how other systems work**

Some family members said that different systems (e.g. schools, agencies, government) were not working together. Each system has its own set of rules and goals that are different from other systems. This made it difficult for some families to get support from systems.

Some parents said that school staff did not know what services were available after young people left high school. Other family members found the child system and adult system to be very disconnected (separate and mismatched). This disconnection got in the way of a smooth move from high school to adult life.

Some parents also wanted help with paperwork and other details to help them find their way with these systems but that help was not there.

### **Panic (fear) planning**

Another theme (idea) that many family members talked about was fear based planning. This is planning that takes place at the last minute which means there are not many choices. These choices were often ones that were not a good fit for the person. However, because families were afraid of having no supports, they were willing to take whatever they could get. In some situations, transition

planning was taking place at the end of the final school year (June). Such late planning meetings meant that families were panicked about what their young person would do next year. One family member said, "...the transitioning doesn't seem to happen until all of a sudden, in a panic, the school says, 'well, you know, they can't come back to school in September.' And this is June, when it should have started a year prior (before) when they were eighteen."

Some parents felt relief after getting a service for their young person. However, over time, some parents wondered if this support was the best fit for their child. Parents wondered what other services are out there? Is there something that is a better fit? The parent was not able to ask these questions before because they were in a panic situation and needed to make a choice. For some families, the fear of having nothing (no supports) for your child may mean you are more likely to take something that might not be the best fit.

### **C. Barriers**

Barriers are those things that get in the way of a young person living the life he or she wants to live. Barriers are also things that get in the way of a successful (good and smooth) move from high school to adult life for young people and their families. This is what people said.

#### **Services are interrupted (stopped) at transition**

One of the biggest barriers (obstacles) to transition for the people who took part in this study was how services were interrupted. There are many parts to young adult transition; they include:

- (a) The transition from high school,
- (b) The transition from child services,
- (c) The transition into a new support system, and
- (d) The transition into a new life stage (from childhood to adulthood).

For example, some parents said that all services ended at age 19. Then families were in limbo (in between two different things) when the young adult was not getting any supports, and families were waiting to find out what options they would have. This may mean waiting to hear from CLBC about how much funding (money) would be available. It may also mean waiting to hear if their son or daughter was able to stay in school for an extra year. In many situations, this waiting led to panic planning as decisions were not made until the last minute.

The experience of transition for young people and their families can be described as the black hole.

*"When all of these individuals leave school, there's just a hole. They hit a brick wall, there is nothing, absolutely nothing suitable out there for them, and they're left swimming around in this deep water adrift and it's so sad."*

Some parents were worried there would be no services once their child turns 19. Parents described transition as a time in which *"so much stops...it's a complete cut off."* Another parent said, *"I think my son will live to be a ripe old age given the genes he has and I'm concerned that I don't want him to sit and watch TV for the rest of his life."*

### **Not knowing about options**

Many parents said they did not know what the options were for their son or daughter after high school. Some parents also said that social workers/facilitators and the school system did not know of the many options available for the young person. Some family members said they didn't have the time to research and learn about all of the options in the community. This was because such research was seen to take a lot of time.

When speaking to young adults about the planning process, some said they had ideas about how they wanted to spend their time once high school was over. Other young adults said they did not know what they wanted to do.

### **Focusing on problems and disabilities**

One parent talked about how he had to paint a negative picture of his family and son in order to get crisis (emergency) support because they were not able to get any other kind of support. This was a hard experience for the family. Focusing on problems and difficulties goes against the values of person-centred planning. This type of planning is supposed to focus on the strengths, abilities, hopes, desires, and needs of the young person.

### **Giving up on the system**

Parents talked about their experiences with CLBC and social workers/ facilitators during transition. Most parents who took part in this research had poor experiences with this system. Family members said that promises were not met and they often had to wait a long time to hear back from CLBC and staff. Some parents talked about how they were told by government workers that the dreams and/or plans they have for their child are unrealistic (unlikely). These experiences led families to give up on this system.

## **D. Gaps**

This section is about those parts of the transition process that were missing or were needed. Families and young adults were asked to talk about those supports that were missing during the transition experience. This is what people said.

### **Isolation (loneliness) after leaving high school**

Isolation (loneliness) was a concern at the time of transition as young people are leaving school and their supports/services are changing. Some parents talked about the "great" programs their children were able to be involved in before

turning 19. They explained that once their children became adults, they were no longer able to enjoy the same services. For many young people, programs gave them an opportunity to make friendships. When they are no longer able to take part in these programs, it can be difficult for these friendships to continue.

Some parents worked together to make sure there were supports that young people could take part in as they move into adult life. These supports helped to make sure that young adults in transition could stay connected with friends and get out in the community.

The idea of belonging is important during the high school to adult life transition. This is because these young adults no longer belong in the school system but are not ready to get adult services. People who took part in this research said having a place to belong during and after transition was important.

One parent explained the difficulty with belonging: he said, *"She's trying to find a place where she can be. There's just very, very little support. She's 19, she doesn't want to sit in a room with 40, 50 year olds that have nothing in common with her."* Once young people leave high school, it can be hard for them to find places to be with friends of the same age.

### **E. Desires/Aspirations (hopes and dreams)**

Family members and young people were asked to talk about what would improve the transition experience.

#### **Wanted supports**

Many parents talked about supports they wanted to see as part of the transition process. One parent said she wanted some counseling support for her child and the family during the transition. This service was not available at that time. Another parent wished there was a transition planner who would help families and young people connect with good supports in the community. One family member

talked about having a professional planner help families during transition. She believed this would be a helpful support.

### **A list of supports with instructions on how they work**

Some parents wanted to have a list of community living supports in a community to help them plan for their young person. Parents believed that this list would help people know about all options. Some family members said that they had a hard time planning because they were not sure what the support options were. Families also said that researching all of the options takes too much time.

One parent thought it would be helpful to know what good things certain programs were doing. She thought this might help other programs start doing these good things too.

### **Service overlap (having some services continue)**

Many families wanted services to overlap rather than have them all end at once. Parents thought this might make the transition from high school smoother. Many families said they were often told that there were no available supports and no available funding (money).

### **Personal/counseling support**

Some families said they would like some emotional support (support for people's feelings) during transition. Some people who took part in this research said they wanted to have some counseling for the entire family. Transition is a stressful time for young people and their families. One parent said it would be helpful to know that they would have someone checking in on them once in a while.

### **Funding (money) that is guaranteed over time**

Instead of having money for a short time, one parent wanted a promise that they would have money for a long time. Most of the time money is only promised for a

short time. This kind of money helps for secure (safe and protected) planning rather than planning that is only guaranteed for a year.

## **F. Other ideas**

This part of the report includes themes (ideas) from people's stories that do not fit into the other parts of the report.

### **Activities for after high school ends**

Young adults who took part in this research did many different activities after leaving high school. Examples of these activities included:

- Day programs
- Work/career day programs
- Volunteer work
- College program (e.g. Capilano College, Vancouver Community College)
- Activities with friends
- Special Olympics
- An extra year in high school
- Support groups
- Activities with family
- Creative hobbies (e.g. pottery, music).

In some communities (towns), usually small communities, people said there were not many options for activities after high school. Young adults and family members who took part in this research said they wanted more work opportunities.

### **Young adult experience of transition**

Young adults had many thoughts about their experience of leaving high school. This is what they said.

### Feelings about transition

Some young adults found it hard to leave high school. Some young adults said it was good to leave high school. For some it was hard because they were leaving behind friends and teachers. For others, leaving high school was a good experience because it meant there would be more time to do other, more interesting activities (e.g. see friends, do hobbies).

### Change in status/relationship

One young person said leaving high school gave him feelings of "*freedom*". He also said he felt more "*adult like*", "*capable*", and "*responsible*".

### Next steps

Some young adults who took part in this research had lots of ideas about what they wanted to do when high school was done; others said they had "no clue". For example, one young adult said she wanted to go to university. Another young adult said he wanted to start working. For some people there were many things that got in the way of taking part in those things they wanted to. For example, there were not many opportunities (choices) in some small towns. Another young woman wanted to work in the kitchen of a restaurant; but, because of changes in her health, she was no longer physically able to be a cook in a restaurant.



**Conclusion (final words)**

The information in this report shares some of the stories, opinions, and hopes of family members and young adults throughout B.C. who took part in this research. This type of research is not meant to be true of everyone's experience. However, the information in this report gives useful and important information about how young adults and families are supported; and how they hope to be supported in the future.

## Glossary

**Non-residential supports:** are things that people do during the day and night. For example, day programs, work.

**Remote:** is a word used to describe far off places or places that are not close to big cities.

**Residential options:** are different types of places where people might live. For example, group home, apartment, with a family.

**Self-determination:** is when people have independence and make their own decisions.