



Young Adults with Developmental Disabilities: Transition from High School to Adult Life

A Plain Language Summary

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This review was prepared by the *Community Living Research Project* based at the School of Social Work and Family Studies, 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 Adults with Developmental Disabilities: Transition from High School to Adult Life" produced by the Community Living Research Project.

To help people read this 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.

To make reference to research, footnotes have been used in this report. Footnotes are noted in the report by a small number at the end of a sentence; the number can also be found at the bottom of the page followed by the researcher's name and the date of the research referenced. If you need more help reading this paper, please ask a friend.

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Introduction

As young people prepare to leave high school, they have new parts of their lives to think about. This time of transition (change) includes life adjustments and new experiences as these individuals move from school to independent living and working.¹ However, researchers state

"The opportunities and challenges that await them [youth with disabilities and their families] in the adult community are very unclear and depend heavily upon numerous circumstances [situations] such as local economies [how rich or poor a place is] and job opportunities, residential and transportation services, and community awareness and support for persons with disabilities."²

Research discusses the limited outcomes (results) for young people with disabilities in the areas of employment, post-secondary education programs (college and university courses and programs), and adult community services.³ Young people with developmental disabilities identify the following as important in their lives:

- Getting a job,
- Spending time with friends and family,
- Having "adult" status (e.g., having a space or place of their own), and
- Self-determination* (independence and making one's own decisions).⁴

¹ (Wehman, 2001)

² (Wehman & Revell, 1997, p. 66)

³ (Beresford, 2004; Florian et al., 2000; Johnson et al., 1997; National Collaborative on Workforce and Disability, 2006)

⁴ (Cooney, 2002)

The supports most frequently needed, requested, and received for young adults with disabilities 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.⁵

The transition from school requires all students to participate in some preparation. For students with a disability, this preparation may be a more active and complete process. Ideally, planning will focus on the strengths, abilities, and interests of the young person.

Transition can be a hard and frustrating process as individuals and families try to understand and ask for support from a new service system. Issues of eligibility, costs, person-environment fit (do the needs, interests, and abilities of the person fit with what a service offers?), and waitlists are some challenges individuals and families may face.⁶

Some researchers have stressed the difference between transition from child to adult *services* and the process of transition from child to adult *status* (becoming an adult, no longer a child).⁷ Often times the focus of the transition is on moving into new services. Some research suggests that people see the transition process as supporting a young person to move into a new life stage.⁸

⁵ (Johnson et al., 1997)

⁶ (NICHY, 1994)

⁷ (Beresford, 2004)

⁸ (Beresford, 2004)

There is not a lot of research looking at options after high school for young adults with severe developmental disabilities. Most research focuses on young people with mild disabilities.⁹ For young adults with severe developmental disabilities, transition often means a move from a special education school system to an adult service delivery system* (the organizations and agencies that offer supports and services to adults).¹⁰

It is difficult to understand the issues and experiences of these individuals. It is also difficult to find approaches (ways) to support the needs, hopes, and interests of these young people.

Research looking at outcomes (results) for individuals with severe developmental disabilities has found that:

- Few individuals with severe disabilities work competitively* (working in typical jobs in the community making the same pay as those individuals without disabilities),
- Earnings (the amount of money made through a job) are low, and
- Social isolation (separation from friends, spending time alone) after leaving high school is high.

⁹ (Clegg et al., 2001)

Social networks* (relationships with people you spend time with) of young people with this level of disability are made up of a smaller number; this is compared to the networks of peers (people of the same age) without disabilities or with mild disabilities.¹¹

Transition Planning

In the United States, the Individuals with Disabilities Education Act (IDEA, 1990) mandated (required) that student individualized education plans* (IEPs; a written plan for a student's special education that outlines goals, abilities, needed supports, etc.) include a transition section by the time the student reached 14 years old. A more detailed transition plan was to be outlined by age 16.¹²

Some researchers have suggested the IEP* be used throughout the school years and for the many transition that occur (e.g. pre-school into elementary school, elementary school into middle school, etc.). This way planning would be a lifelong process starting when a young person enters elementary school and continuing across the school years.

The transition planning process in England is mandated (required) by legislation (laws).¹³ The Special Education Needs (SEN) Code of Practice¹⁴ states that the planning must be participative (involving many participants who work together), holistic (looking at the entire person and his/her life), supportive, evolving (changing as needed), inclusive, and collaborative (combining the efforts of all people involved).

¹⁰ (Kraemer & Blacher, 2001)

¹¹ (Johnson et al., 1997)

¹² (deFur, 2003)

¹³ (The Education Act of 1996, available online at: www.opsi.gov.uk/acts/acts1996/1996056.htm)

¹⁴ (Department for Education and Skills, 2001, p. 131, Section 9:52)

Transition planning for individuals with disabilities in England follows a step-by-step process that begins when the youth reaches 13 years of age.¹⁵

In England, young people getting ready to transition from school to adult life can contact a government support service. This service is the Connexions Program (www.connexions.gov.uk) which is available to **all** young adults preparing to enter the adult world.¹⁶ In each school there is a Personal Advisor (PA) who meets with the student and family when the student turns 13. The PA advocates (supports and speaks on behalf of) for the student and his/her family.¹⁷ The school and the PA work together to create the transition plan which will then be given to the student and family.¹⁸

However, even though there is legislation (laws) and step-by-step guidelines for transition planning, research found that many youth find the process disappointing.¹⁹

Literature (books and articles) makes several recommendations that will lead to better results for young adults as they prepare to transition from high school.

Recommendations for the School Experience:

- School curriculum (courses, classes, topics) should include self-advocacy (learning about your rights) and self-determination* skills building;²⁰
- Interpersonal skills (e.g., communication), on-the-job skills, and on-the-job training should be practiced while in school;

¹⁵ (Trans-active, 2006)

¹⁶ (Department of Education and Employment, 2000)

¹⁷ (Grove & Girard-Saunders, 2003)

¹⁸ (Trans-active, 2006)

¹⁹ (Heslop et al., 2002)

- Youth should have opportunities and experiences in meaningful job placements (work experience).

Recommendations for the Transition Planning Process:

- Young people, parents, and other advocates need to play an important role in planning and decision-making;²¹
- The planning process should be supported by skilled and knowledgeable staff²² who participate in training regarding (about) the transition process;²³
- Each member of the Individualized Education Plan (IEP*) team should understand his/her role;²⁴
- The transition process should be seen as flexible and long-term;²⁵
- Thoughtful decision-making should involve opportunities for young people to try out different jobs;²⁶
- Transition teams should be comprised (made up) of students, families, businesses, and community representatives;
- Services between vocational agencies (job search and placement agencies), regular and special education teachers, and counsellors should be coordinated (planned to help things run smoothly);²⁷
- Follow-up services should be provided until the student has connected with adult services.²⁸

²⁰ (National Council on Disability [NCD], 2000)

²¹ (Beresford, 2004; Cooney, 2002)

²² (Beresford, 2004)

²³ (National Council on Disability [NCD], 2000)

²⁴ (Avoke, 1998)

²⁵ (Beresford, 2004)

²⁶ (Sax & Thoma, 2002)

²⁷ (National Council on Disability [NCD], 2000)

²⁸ (National Council on Disability [NCD], 2000)

Tools/Methods for School-based Transition Planning

Literature (books and articles) also discusses some specific tools (techniques or methods) to help with the transition planning process. These tools work with people who support young adults with developmental disabilities. Also, the tools help people get organized and aware of what is coming in order to successfully deal with the challenges of the transition process. For example, one tool has teachers get out into the community to learn about the supports that exist. Other approaches outline models (guides) for teachers, counsellors, and other professionals in providing instruction and support in the areas of social skills, learning skills, and work skills.

Some tools also provide opportunities for young adults with disabilities to audit (to take a class without receiving a grade or credit toward a degree²⁹) college courses before finishing high school. Another model describes a partnership among the special education system, the rehabilitation system (the organization in the United States responsible for helping a person achieve the highest level of function, independence, and quality of life possible³⁰), and the disability support system. Through combining the services, supports and resources of these systems, a smooth transition can take place.³¹

Some of these tools have been used and evaluated and show good results. Other tools have been described but have not been evaluated through research.

²⁹ www.lindentours.com/int_students/glossary.shtml

³⁰ ymghealthinfo.org/content.asp

School to Work Opportunities

Work is a reasonable and desirable next step for many young adults graduating from high school. This is also true for young adults with developmental disabilities. However, work opportunities and experiences for these youth are unpredictable (random and irregular) and employment options are limited.³²

In 1994, the United States introduced the "School-to-Work Opportunities Act" which was legislation (laws) designed to guide the transition to work for all students. According to the U.S. Department of Education, this act was created to help "prepare all students for work and further education, and increase their opportunities to enter first jobs in high skill, high wage careers."³³ After the introduction of the School-to-Work Opportunities Act many projects throughout the United States were created. These projects dealt with the employment needs of all youth and specifically, youth with disabilities.

Some school-to-work programs are designed to support young adults with mild/moderate developmental disabilities. Examples of programs for youth with mild/moderate disabilities include:

- Opportunities to job sample* (spend time learning about and participating in many different jobs),
- Receive general job skills support and instruction (teaching), and
- Receive support in specific fields (e.g. technology).

³¹ (Luecking & Certo, 2002)

³² (Johnson et al., 1997)

³³ (as cited in Benz & Kochhar, 1996)

Throughout the world there are also college/university programs for young self-advocates* (young adults with developmental disabilities) that help these young people get into the workforce.

Other programs are designed to support young adults with severe/profound disabilities.

Examples of school-to-work programs for these include:

- Support options for employers to help in capacity building (increasing employers ability to successfully employ people with severe disabilities),
- Individual support as each student learns and masters a job related skill,
- Specific transition planning support that focuses on post-school (after completing high school) goals and self-determination*
- Instruction (teaching) in academic, vocational (work), independent living, and personal-social (e.g. making friends) topic areas,
- Paid job training, and
- Mentor (a person who guides another person) support with professionals in a range of fields (jobs or professions).

Community Support

There are programs that function in the community that help young people with the transition to adult living. These programs may be independent from the school system (operate without the support of the school system) or they may connect with schools as a way to reach young adults.

By working on a small scale (e.g. supporting only 5 young adults at a time), some of these community supports enable (help make it possible) young people to live the unique life they desire for themselves.

Other supports provide a place in which young adults can:

- Obtain information,
- Share concerns, and
- Connect with other young adults facing similar challenges.

Canada: Transition Planning in the School

In Canada, provincial governments are responsible for organizing education and outlining procedures for the transition process for young self-advocates*.

Alberta

Alberta Education (2006), the government ministry (department of the government) responsible for special education, outlines transition planning for four transitions:

- (1) Elementary school,
- (2) Junior high school,
- (3) Senior high school, and
- (4) Post-secondary settings.

In Alberta, school personnel must organize the transition plan in a way that is in line with the IEP*.³⁴ Also, the planning must involve:

- The student,
- The family,
- Other professionals, and
- Community agencies.

Manitoba

In Manitoba, collaborative planning* (planning involving all necessary individuals and agencies with all participants working together) was required for all students with special needs age 16 and older who would need government support after leaving school.³⁵

The special education coordinator is responsible for starting transition planning meetings for students who meet the above criteria.³⁶

Ontario

Ontario Regulation 181/98³⁷ states that students age 14 years or above determined to be “exceptional” (this would include most students with disabilities) must have an IEP* that includes plans for transition.³⁸ The principal is responsible for making sure that the IEP* include a transition component by age 14. The principal must also make sure that appropriate individuals (e.g. community agencies) be involved in the transition planning.

³⁴ (Alberta Learning, 2000)

³⁵ (Manitoba Education, Training, and Youth, 2001)

³⁶ (Manitoba Supported Employment Network, d/u)

³⁷ (as amended Ontario Regulation 137/01)

³⁸ (Ministry of Education, Ontario, 2002)

As of March 2006, the Ontario government launched the "Passport Mentoring Initiative", a new mentoring program for youth with developmental disabilities with:

- The Community Inclusion Project,
- People First of Ontario, and
- Local school districts.³⁹

The "Passport Mentoring Initiative" is intended to help youth (14-21 years) with a developmental disability successfully transition from high school. Students who become involved with this initiative (plan) will be paired with experienced, adult mentors (guides) who also have a developmental disability.

New Brunswick

In New Brunswick, transition planning for all students begins in grade 6 with the "Linking to the Future: Career and Educational Planning Portfolio". However, such planning becomes more focused for youth with special needs in grade 8.⁴⁰ It is the responsibility of the school-based team to initiate (start) such planning.

Nova Scotia

The Department of Education in Nova Scotia has created a transition guide for parents, students, and practitioners that focuses on the transitions that take place throughout the school experience. According to the guide and the Special Education Policy Manual⁴¹, transition planning is a "...required component of individualized program planning."⁴²

³⁹ (Ministry of Community and Social Services, Government of Ontario, 2006)

⁴⁰ (New Brunswick Department of Education, 2001)

⁴¹ (Nova Scotia, Department of Education and Culture, 1997)

⁴² (Nova Scotia, Department of Education, p. 3)

British Columbia

In British Columbia, each student needing help with his/her education will have an IEP*.⁴³ The IEP* is created by:

- The teacher,
- The parent/guardian,
- The student,
- The school administrator, and
- Other school based personnel.

It is a flexible, concise (brief) document that outlines the student's education plan.

To help youth, their families, and those who support youth, the Ministry of Children and Family Development created two documents; the community support guide, entitled "Transition Planning for Youth with Special Needs", and the youth and family guide, entitled "Your Future Now" (guides are available at http://www.mcf.gov.bc.ca/spec_needs/adulthood.htm).

However, transition planning in B.C. is not mandated (required) and there is no province-wide or region-wide policy (rule guiding action). This process is often different in different school districts and specific schools.

The Community Living research team distributed (sent out) surveys to special education representatives throughout the province. The purpose of the surveys was to better

understand the transition planning approach that school districts in B.C. use. Out of the 60 surveys distributed, 17 surveys were returned.

Less than half of the participating school districts said they had a policy or process guiding transition planning in their district. The most commonly quoted process was the IEP* used with PATH* (a process of person-centred planning) and the Ministry of Education transition planning materials. All schools reported that special education teachers have the primary responsibility for creating a transition plan. Other people identified as involved in the process were:

- Parents,
- Social workers,
- Students, and
- Principals.

Special education teachers were also reported as the main person responsible for monitoring (supervising) plans to make sure they are created and put into practice; parents, principals, and case managers were also reported as having this responsibility. In one survey response, the representative indicated that no one in their school district had this responsibility.

⁴³ (Ministry of Education, 2005)

Community Living Associations

All provinces in Canada have a provincial Community Living Association offering information about services, supports, and organizations within each province (www.cacl.ca/english/provteracts/). Also, many regions within each province operate Community Living associations or societies. These associations often offer programs/supports to meet the needs of individuals with developmental disabilities and their families. Each association offers different programs and has varying levels of capacity (differ in how many people they can support and in what ways).

Generally, most community programs/supports for young adults in transition focus on:

- Building independence,
- Providing education and employment options,
- Offering instruction in life skills (for example, social skills, money management, personal care, etc.), and
- Goal setting.

Workshops and seminars are also available for parents to help them support their child through the transition.

Internet Communities

Internet communities* (a group of people who use their computers to talk and work together) are another resource for young people and their families preparing for transition. Information about services and opportunities are often listed here as well as reports and books on areas related to individuals with disabilities. Some online

communities offer chat areas which invite people to ask questions and connect with other individuals living similar lives. Examples of such communities include:

- National Education Association of Disabled Students (www.neads.ca) and
- Disability Ontario Online Resource for Transition to Adulthood (www.ablelink.org/public/transition/default.htm).

Inclusive Post-Secondary Education

Inclusive post-secondary education* (education at colleges or universities in which students with and without disabilities are in the same classes) is an option for young self-advocates* in some areas of Canadian provinces. Some university programs provide inclusive education opportunities for any young adult wishing to pursue post-secondary education and in some cases, regardless of disability level.⁴⁴

Examples of such programs include the:

- On-Campus Program (University of Alberta),
- STEPS Forward Program (www.steps-forward.org, University of British Columbia, Emily Carr Institute, University of Victoria) and
- College Connection Project (Grant MacEwan Community College, Edmonton).

The idea behind the On-Campus Program is to provide young self-advocates* the opportunity to participate in an environment that encourages growth and self-development.

"Postsecondary education provides most young adults with a natural pathway into adulthood. There is no such process available for young adults with developmental disabilities. They are expected to go immediately from being high school students to being adults, ready for full-time work and a life of independence."⁴⁵

British Columbia: Transition Support

In 2005, Community Living British Columbia (CLBC, www.communitylivingbc.ca) was created and took over responsibility from the Ministry of Children and Family Development (MCFD) for the Community Living services in the province of British Columbia; such services were previously managed by MCFD. The role of CLBC is to:

- (1) Help individuals and their families figure out what they need, and make a plan to get it,
- (2) Work with individuals, families and communities to create new ways of providing support, and
- (3) Decide who gets paid services and then organize those payments.

CLBC has two different staff positions to work with individuals and families helping them get the support they require – the facilitator and the quality service analyst. On June 29, 2006 CLBC released information outlining a new initiative (plan) in the area of transitioning young adults with disabilities and innovation (originality).

⁴⁴ (Bowman & Skinner, 1994; STEPS Forward, 2006; Weinkauf, 2006)

⁴⁵ (Bowman & Skinner, 1994, p. 1)

It stated,

"...\$300,000 has been set aside for fiscal year 2006 to enable community partners to identify new ways to support young adults with developmental disabilities who have left school within the last three years. The funds will be awarded to those innovative projects that encourage employment opportunities or engage [participate] in meaningful community activities."

As with other provinces in Canada, B.C. has several Community Living agencies in communities and each offers a variety of Community Living programs and services. Several of these associations offer some transition support; however, the way the support is organized and the topics and activities of the support are different.

Types of transition support available through Community Living associations for young adults includes:

- Networking groups,
- Day programs that focus on life and employment skills, and
- One-on-one support.

The requirements a person must meet to be able to participate in such services varies (are different).

Post-secondary education (education a person takes after completing high school) is also an option for young self-advocates*. Each college and university in B.C. provides disability support services (e.g. note taker assistance, exam and classroom adjustments).

Beyond these services, there are several colleges/universities that offer programs and courses designed specifically for adults with disabilities and special education needs; they are not typically inclusive settings but students in such programs have access to and can participate in "typical" campus activities (e.g. attending sports events, eating in the cafeteria, joining clubs). Most of these programs offer:

- Employment skills,
- Life skills,
- Consumer skills (e.g. how to shop and buy items), and
- Job specific training in classroom and community settings.

However, these courses are often segregated and have several eligibility requirements. Such requirements often include the ability to complete standard coursework and communicate verbally. These criteria may exclude young adults with severe developmental disabilities.

Examples of these college programs are a based on the 2005 Resource Directory of Programs and Services for Students with Disabilities in Public Post-Secondary Institutions (see <http://www.aved.gov.bc.ca/adultspeialed/resource/welcome.htm>).

Areas for Further Exploration

1. Is transition planning actually based on individual's aspirations (hopes and desires) or is transition planning based on available adult services? We know that planning is *supposed* to be focused on strengths, abilities, hopes and dreams, but what kind of planning *actually* takes place?
2. Once a transition planning process that is based on young people's aspirations (hopes and desires) occurs, the question then becomes – are these plans made a reality? Are the plans followed through on or do they remain plans written on a piece of paper?
3. Do the options and supports currently available to transitioning young adults reflect the needs and desires of an earlier group of young adults? Do young adults these days want and/or expect different support options than those that currently exist?
4. Are options now inadequate or unsuitable for this new cohort (group) of young adults with developmental disabilities who have different inclusion experiences? To clarify, many of the young adults preparing to transition have likely been in integrated and inclusive settings throughout their childhood; given this type of experience, do these young adults have different expectations or ideas about how they want to be supported once they exit high school?

5. Deb Rouget states that "...people will not automatically create better unless they can see examples of what's possible, understand the reasons why better should be achieved, what should be done, the theories and ethics that should underpin such efforts, how people can be safeguarded and how such efforts can be operationalised [defined in a specific way] in practice." (p. 12). This raises the question – how can people be exposed to examples of the possible?

Conclusion

Transition from high school brings new life areas into focus for thought and planning. Planning for the future following high school takes place on some level for all students. For young self-advocates*, transition planning focuses on post-secondary education, employment, and day programs. However, research has demonstrated poor results in these areas for these young adults due to a number of factors (e.g. poor planning, learning about an unfamiliar system, waitlists, and eligibility criteria).

Young adults with severe developmental disabilities experience even poorer results. Lack of research (not much research) exploring the needs, possibilities, and desires for these young adults and the ways they can be effectively supported presents challenges to having strong results.

Transition from high school to adult and community life is often a challenging process for young adults with developmental disabilities and their families. However, the lives these young people wish to live include many of the same things as those young people without disabilities.

According to many young adults with developmental disabilities, areas of life that are important include:

- Spending time with family and friends,
- The recognition of a change in status (now an adult, no longer a child) accompanied by autonomous (independent) decision-making (self-determination*),
- Possession of personal space (e.g. having one's own place), and
- Employment and money are areas of importance.

In learning about the needs and dreams of and the possibilities for young adults with disabilities, we can work to better support these individuals.

Glossary

Adult service delivery system is the organizations and agencies that offer supports and services to adults (mentioned on page 7).

Collaborative planning is planning involving all necessary individuals and agencies with all participants working together (mentioned on page 15).

Individualized Education Plan or IEP is a written document that outlines a student's special education plan including needed supports and accommodations. It also includes goals and learning expectations related to the student (mentioned on pages 8, 10, 15, 17, 18).

Inclusive post-secondary education is education at colleges or universities in which students with and without disabilities are in the same classes (mentioned on page 20).

Internet communities are a group of people who use their computers to talk and work together (mentioned on page 19).

PATH stands for "Planning Alternative Tomorrows with Hope" and is a tool for person-centred planning (mentioned on page 18).

Self-advocates are, for the purposes of this report, young adults with developmental disabilities (mentioned on pages 13, 14, 20, 22, 25).

Self-determination refers to having independence and making one's own decisions (mentioned on pages 5, 9, 13, 26).

Social networks are relationships with people you spend time with (mentioned on page 7).

Work competitively means working in "typical" jobs in the community making the same pay as those individuals without disabilities (mentioned on page 7).

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