

Feasibility Study on the Programming Needs of Young Adults with
Down Syndrome

C.H.A.N.G.E.S. Down Syndrome Support Group

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Research Questions

Young adults with Down syndrome Survey Questions

1. Do you reside with a parent/guardian?
2. How many day programs do you currently attend?
3. Are these public programs?
4. Are the programs accessible?
(affordable, support personnel available, transportation)
5. Are programs available to you year-round?
6. How many hours a week do you spend in day programs?
7. What is the duration of most programs?
(number of weeks/months, seasonal)
8. Please describe a typical day in your life?
-what did you do after you had breakfast?
-when do you leave your home? etc.
9. What types of day programs benefit you the most?
(training/education, life skills, social functions)
10. What type of day programming do you enjoy the most?
11. What type of day programming would you like to see more of?
12. If you were not enrolled in any day programs, what would you be doing instead?

Service Providers Interview Questions

1. Does your membership/clientele include person's with developmental disabilities?
If so, approximately how many?; age group?
2. How do you receive most of your clients? (are they referred to you or do you actively recruit clients)
3. Is there a waitlist for enrollment in programs?
4. What is the intended duration of a client's membership?
5. Do you provide services/support/programs for...
 - life skills development (cooking, banking, etc.)
 - education (certified courses, tutoring)
 - vocational training (work placement, employment counseling, training)
 - social functions
6. How are your programs structured?
7. Are these public programs?
8. Who determines whether a client is eligible for a program?
9. Are they available year-round?
10. Are they offered on an individual basis or in small groups of clients?
11. When enrolling in programs (before, during, and after)
 - What are the responsibilities of the client?
 - What are the responsibilities of the organization?
12. Do you work in tandem with any other community groups? Locally and abroad?
13. How are you funded?
14. Do funding bodies pose any restrictions on your organization?
15. What is the goal/vision of your organization?
16. What is your organization's greatest strength in achieving this goal?
17. What is your organization's greatest weakness in achieving this goal?

Research Synopsis

Response from young adults with Down syndrome

After consulting with members of *CHANGES* it is evident that a network of support programs are needed in order for young adults with Down syndrome to have equal opportunity and access to participating in society and realize an overall sense of well-being. Noteworthy aspects of life that require support and accommodation include- but are not limited to-employment and vocational training, life skills (i.e. cooking, banking), and inclusive social functions. All support programs should be directed toward increasing self-sufficiency and empowering those that it intends to serve. Support programs that are developed should be accessible. This means that programs are affordable, available year-round with flexible schedules. Transportation issues should also be taken into account, with programs that are adaptable to the individual. Without such programs life for young adults with Down syndrome is dependent on their parent/guardian as society prevents them from realizing their full potential.

Service Providers

Community Living, Peterborough

Community Living Peterborough has a wide variety of services and programs for supporting persons with developmental disabilities. Although programs may not be accessed immediately and require clients to be waitlisted, programs are available free of charge on a continuous basis that includes life skills training, education, employment support, and social functions. *Community Living* is primarily focused on providing services on an “as needed” basis, whereby clients identify a specific need they may have for ensuring quality of life.

I find that the greatest asset of *Community Living* is its extensive network of connections to resources and partnerships with other organizations in the community. This network can be utilized for integrating persons with developmental disabilities into the community in order to ensure equality. It is also commendable that *Community Living* strives to accommodate the individual while offering a wide range of programs and services.

However, *Community Living* lacks a well developed program that takes into account the needs of young adults with developmental disabilities (aged 21-30 years). Programs are often inaccessible as members are placed on waitlists for varying lengths of time. *Community Living* also requires clients to provide their own transportation as program attendance is the responsibility of the client. Therefore, there is a significant gap in services for young adults with developmental disabilities, and services that are available have some accessibility barriers.

Alternatives

Alternatives assists adults with developmental disabilities achieve their goals in life and live interdependently in the community. They offer at least seven different programs that develop life skills, provide employment supports, social functions, and provide assistance to individuals seeking education or accreditation. *Alternatives* provides many of its programs on a one-on-one basis, in which clients receive individual attention from a devoted staff member. Clients of *Alternatives* are advised to formulate a life plan consisting of short-term and long-term goals, which the client is encouraged to pursue with support from *Alternatives*.

I believe *Alternatives* provides a uniquely personal and individualized service to clients, who are supported in various aspects of life. The organization also has programs that target youth and young adults with developmental disabilities in particular for meeting their needs. In this respect, “Foundations”, is a specific program dedicated to servicing the transition after graduating from high school that recognizes the lack of services for this demographic.

It has been brought to my attention that *Alternatives* requires more funding in order to service more clients and eliminate the waitlists that exist for the majority of its programs. Moreover, clients are responsible for providing their own transportation and the “Fundamental Skills Development” program requires a fee-for-service. These conditions pose barriers on clients accessing programs.

Feasibility Study on the Programming Needs of Young Adults with Down syndrome

Purpose of the Report: To outline the day programming needs of young adults (aged 21-30) with Down syndrome in the Peterborough community and make recommendations.

Background to the Report

Individuals with Down syndrome graduate from high school at the age of 21 with limited opportunities for further education, employment, and overall participation in the community, which is necessary for living a productive and meaningful life. Due to the nature of their disability they require community resources and accommodations from society in order to reach their full potential.

Methodology:

1. Consulted members of *CHANGES* (young adults with Down syndrome) to understand their current situation and what they wanted out of programs that services their needs
2. Interviewed service providers (*Community Living, Peterborough, and Alternatives*) who currently provide day programs and services to persons with developmental disabilities
3. Conducted supplementary research on service providers from secondary sources
4. Analyzed research and made recommendations

Findings from Research

Young adults with Down syndrome require support programs that are...

- Dedicated to increasing self sufficiency and empowering individuals i.e.) employment, vocational training, life skills, inclusive social functions
- Accessible to those they are meant to serve i.e.) affordable, accommodating, available, considerate of transportation needs

Service Provider	Strengths	Weaknesses
Community Living, Peterborough	<ul style="list-style-type: none"> • Has an extensive network of connections to resources and partnerships with other organizations in the community • Strives to accommodate the individual while offering a wide range of programs and services 	<ul style="list-style-type: none"> • Lacks a well developed program that takes into account the needs of young adults with developmental disabilities (aged 21-30 years) • Programs are often inaccessible as members are placed on waitlists for an indefinite period of time • Requires clients to provide their own transportation as program attendance is the responsibility of the client
Alternatives	<ul style="list-style-type: none"> • Provides personal and individualized service • Clients are supported in various aspects of life • Has a program that targets 	<ul style="list-style-type: none"> • Waitlists exist for the majority of its programs • Clients are responsible for providing their own transportation

	young adults with developmental disabilities (“Foundations”)	<ul style="list-style-type: none"> • The “Fundamental Skills Development” program requires a fee-for-service from its clients
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Analysis

- *CHANGES* members and service providers share the same goal in terms of the future for persons with developmental disabilities
- Generally programs service a wide variety of needs and provide the appropriate accommodations, while remaining affordable
- The majority of programs that exist are unavailable as clients are waitlisted for an indefinite period of time
- There is a lack of program supports and services for young adults with developmental disabilities
- There is a patchwork of services as many are provided on an “as needed” basis
- There is a focus on transition planning, but a lack of transition programming to support young adults with developmental disabilities
- Transportation is a significant accessibility issue for *CHANGES* members, especially since it is the client’s responsibility to provide transportation

Recommendations

The gap in program supports for young adults with disabilities (aged 21-30) needs to be addressed by all stakeholders

- Financial support is required to specifically establish a permanent program that addresses the needs of young adults with developmental disabilities
- Existing programs should be extended to eliminate waitlists and ensure equal access
- Service providers should create a network to share information and resources when serving the needs of the same clientele, avoid overlapping of services, while other areas are lacking services
- Transportation issues need to be resolved for those who are having difficulty accessing available programs for this reason
- There is opportunity for social organization among young adults with developmental disabilities who may find it beneficial to create an advocacy group or social enterprise of their own