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Service Expectations for the Future: Results of Family Focus Groups

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For**

Workforce
2010 *Developing a responsive and sustainable
workforce to support children, youth
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Introduction

As part of their vision to secure an adequate rehabilitation workforce in the future, Workforce 2010 sought to identify the service needs of people with developmental disabilities. One aspect of this was to question the family members of those receiving services to determine what they required from support providers. This was done through a series of focus groups with family members conducted throughout the province. These discussions were intended to obtain the vision of the quality life which family members hold for individuals receiving services, as well as their expectations of the support providers in helping to achieve this vision.

The questions used in the focus groups were developed by the VRRRI. Focus groups were facilitated by a consistent member of AARC in all regions. Raw data was then sent to the VRRRI where it was analyzed by a researcher.

Focus groups were conducted in Lethbridge, where 15 parents of both adult children and children under age 18 attended; Medicine Hat, where 2 parents of adult children attended; and Wainwright, where 9 parents, 5 of whom have adult children and the other 4 with children under age 18 attended. In addition, feedback from 3 separate family members was also included in this report. In total, information from 29 family members is included in this report.

The following is a summary of the highlights of these discussions.

Future Supports and Services

Vision of family member's current life

The majority of family members indicated that they believe their family members with a disability should be leading lives that are as similar to those of the general population as possible. Thus, the emphasis is on normalcy rather than being seen as different or disabled, even in cases where support is required to help them live normal lives. Aspects of a "normal" life include forming genuine, lasting friendships, and being given the independence to make life choices.

Another focus is on the importance of being involved in meaningful activities such as paid employment, volunteer work, or attending classes at the college or university level. Respondents also envision that individuals live lives that are measured by quality of life standards rather than by productivity and achievement, where activities such as community involvement and socialization are emphasized over work place accomplishments.

Vision for the future

Once again, the focus is on normalcy where respondents stressed the importance of activities such as moving out to live with friends and becoming a contributing member of the community through employment and independence. Respondents do not wish their family members to "live in the diagnosis", thus limiting their potential, but rather they strive to achieve similar goals as the larger population. It was also acknowledged that some individuals would require "natural

supporters” to help them accomplish goals in their natural environment rather than in segregation.

Some respondents realize that in some cases, their family members are limited by their disabilities. While they do not wish for them to be bound by their disabilities, they did state that problems associated with the disabilities posed concerns. This is especially true for aging individuals whose family members stated that they expect the need for personal care to increase as their family member aged.

Respondents indicated that while they believe it is the government’s responsibility to provide opportunities for individuals to be successful, as a society it is important to move towards a value based rather than achievement based standard for quality of living. It is also important that this be reflected in the school and teaching system.

Challenges to the vision of quality of life

The main obstacle identified by respondents to their family member realizing the type of future envisioned for them is overcoming barriers to community inclusion. Respondents believe that a lack of acceptance and community knowledge surrounding individuals with disabilities would be a hindrance. In order for community inclusion to occur, there must be knowledge and acceptance on the part of the community regarding disabilities. The lack of this kind of knowledge was seen as a possible barrier to the envisioned quality of life.

Others also indicated a lack of resources as a challenge to the desired quality of life; for example, financial resources and human resources were both seen as necessary in order to facilitate community involvement.

A final challenge noted is the lack of opportunities that exist for persons with disabilities. Chances for these individuals to live independently, obtain the job positions they want or to share in similar life experiences as their peers were all seen as unlikely. For these respondents, the fact that their family members are not able to experience similar opportunities as peers limits the quality of life that they envision.

Supports and services necessary to overcome these challenges

The overwhelming response was that more community involvement and attempts for normalcy are the best ways to ensure individuals with disabilities enjoy high qualities of life. These include things such as post secondary education, being given similar responsibilities and expectations to their peers without disabilities that were within their limits, creating roles and environments that foster community inclusion, and emphasizing their accomplishments rather than focusing on their shortcomings.

Other forms of support include having support workers who are well trained, knowledgeable and able to teach life skills. In addition, providing support to the family members, as well as receiving support from the family members, are both necessary to overcome challenges. Some indicated that having the adequate amount of financial resources is also needed as is the need for reliable and dependable transportation to aid in community inclusion. Those with aging family members indicated that services geared towards older individuals will also be needed in the future.

The Role of Support Providers

Expectation of a support provider

The primary skills that respondents expect support providers to have are rehabilitation related education and training, which demonstrates an understanding of specific disabilities. Other skills listed include tending to the physical needs of the individuals, for example going to social events, as well as needs related to the specific disabilities. However, the majority of job related skills reported by the respondents were geared towards the emotional needs of individuals, including treating them with respect and nurturing them, and showing compassion and warmth. Respondents also emphasized the need for workers to like their jobs and to have a genuine desire to help the individuals they work with. A final expectation that respondents had of the support providers is the ability to collaborate between the families, individuals they are serving and other service providers in the community.

Characteristics and qualifications of a support provider

Personal values and attitude

Many of the personal attributes that respondents want to see from support providers involve showing personal initiative; qualities such as good time management and financial skill, and the ability to teach these skills to the individuals. In addition, skills like innovation and creativity were mentioned, as well as the ability to be a mediator and facilitator on behalf of the individual. Other professional skills listed include being motivated to seek information in the field and willing to try new practices. Added to these are interpersonal skills such as the ability to communicate with others well, as well as demonstrating compassion and a genuine interest in the job and the individuals they work with. Respondents also indicated that workers should be ethical and caring and live well rounded personal lives.

Basic or specialized training

Respondents all indicated that formal training is desired from those working with their family members including a related diploma, as well as certification such as CPR and First Aid training. Many respondents also noted that they would like workers to have specialized training in the specific disabilities that their family members have. Others indicated that they would like workers to have general knowledge that is tailored to persons with disabilities such as nutrition and community involvement.

Approach

A client-centred approach that not only focuses on the individual receiving services but also allows for some input from family members is what respondents indicated they wanted to see from support providers. They also stated that workers should have consistency, structure and routine in their approach when dealing with individuals.

Attracting workers to the rehabilitation field

One suggestion to attract people to this field is through the education system, for example, having well developed programs from as early as junior high school, or program placements and work experience in the rehabilitation field in high school. It was emphasized that promoting the field from an early age would help attract individuals to work in the field, especially since many

currently see the field as a temporary job rather than a career choice.

Another suggestion is to campaign to increase the status of the field and the appreciation of staff working in the field, in order for it to be viewed as a career choice; this can be achieved by assigning a professional designation to the field. Another way to raise the status of this field is to increase the profile of individuals with disabilities in society by emphasizing community inclusion. In addition, one respondent stated that they believe families also have the responsibility to make workers feel appreciated.

Respondents also stated that they believe raising compensation levels would attract more workers to the field. The onus was put on the government to provide for wage increases as it was indicated that the current pay levels are not sufficient to support a family.

Summary

The concerns raised by the family focus groups reflect much of what was stated by service providers. (Reported in the Workforce 2010 Employer Survey) As with the service provider's surveys, the main issues raised by family members surround compensation, raising the profile of the rehabilitation field and promoting community inclusion. Respondents indicated that support providers should be knowledgeable and skilled, however, it was generally believed that this could not be accomplished with the current pay scale. Furthermore, they placed the obligation on the government to increase funding in this field in order that compensation levels be raised thereby attracting the most qualified workers to the field. Family members were quick to point out that qualified staff not only meant those with education and experience, but also those with a commitment and desire to improve the lives of individuals with disabilities.

Increases in compensation levels and qualified staff were reported as necessary in order to raise the profile of the rehabilitation field, which was also a concern expressed by family members. Other suggestions to increase recruitment in the field were to promote the field as a career choice from an early age, as well as having work experience classes offered in the field in high school.

Finally, family members expressed concern over the acceptance of individuals with disabilities in the community. Issues of community inclusion were raised, with respondents indicating that in order for their loved ones to achieve the quality of life that they envisioned for them, there needs to be more community acceptance of individuals with disabilities. In addition, there needs to be a commitment to continually supporting families and individuals from the society at large.

In conclusion, family members participating in these focus groups have very legitimate and reasonable expectations for the quality of life for their family member with developmental disabilities for now and in the near future. Achieving their vision will require concerted efforts by service providers, government funders and the community at large, to ensure that people with disabilities live as valued members of society