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Positive Experiences Build Capacity for a Successful Transition to Adulthood for Youth with Disabilities

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There has been a great deal of research about the transition to adulthood for youth with disabilities in the past decade (Gorter, Stewart & Woodbury-Smith, 2012). Most of the research has focused on exploring the transition experiences of youth in different locations and within different systems, and learning about the factors that influence this developmental process (Community Living Research Project, 2006; Johnson & Wallmsley, 2010; Stewart, Gorter & Freeman, 2013). In a recent article in *Prevention Researcher*, we synthesized the evidence from a number of recent studies in Canada to identify three key themes:

- A person's condition is only one factor that may influence a developmental transition;
- Developmental transitions are complex; and
- An increased focus on a positive developmental approach is needed. (*Stewart et al., 2013*)

This article presents some practical considerations for families of youth with Down syndrome and other developmental disabilities that fit with the evidence themes above. All of these suggestions acknowledge the complex interactions between person and environment during the transition to adulthood, and they focus on a positive developmental approach that can build the capacity of everyone (youth, families, community members, service providers) towards a successful transition.

Work Experiences

In high school, all youth with Down syndrome can benefit from participating in "Co-op" (Co-operative Education) or work experience programs (Ontario Ministry of Education, 2000). These experiences will build the capacity of the young person for future employment. Research has shown that high school work experiences increases the likelihood of adult employment (Benz, Lindstrom, Unruh & Waintrup, 2004; Johnson & Walmsley, 2010; Wiesner,



Vondracek, Capaldi, & Porfeli, 2003) and also improves a young person's adaptive behaviours in community settings (Burbridge, Minnes, Buell & Ouellette-Kunta, 2008). A recent Canadian study about work-based education programs in Ontario recommended that worked-based programs for youth with disabilities are effective when accommodations are provided and the developmental nature of the program promotes "gradually increasing demands for independence" (Hutchinson et al., 2011, p. 260). Furthermore, work experience in the community can also build the capacity of future employers and community members to relate to and connect with these youth. (Armour et al., 2011).

Families of youth with Down syndrome can support their child to begin to develop work skills through volunteer opportunities in the community and/or part-time or summer jobs, such as a paper route. These types of informal community-based opportunities can lead to future work experiences as adults in the natural community (Burbridge et al., 2008).

Taking Charge of Their Own Information

Youth can be encouraged to start using resources or tools that enable them to begin to take some control over their own information. One example of this type of resource is the YouthKIT "Keeping It Together: Youth Version" (Stewart et al., 2010) which was developed by CanChild Centre for Childhood

Disability Research with the Hamilton Family Network (see www.canchild.ca). Taking control of information is not just about storing, but it also involves making decisions about how the information is shared with an individual or an organization that may be involved with the young person. It is developmentally appropriate for youth with Down syndrome to express a desire to begin setting their own vision and goals for their future. The YouthKIT is a tool which is divided into modules that address domains of transition such as the transition to high school, social activities or transition



to work. When first beginning to use the YouthKIT, youth are encouraged to identify goals and they are then directed to the modules which address their specific goals.

Initiating the process of goal setting and planning how those goals will be attained can be difficult for youth who may be experiencing some autonomy for the first time. Our research has found that in order to get started, many youth need "mentors" to facilitate completion of modules (Freeman et al. submitted). Mentors can be different individuals around the youth, such as a family friend, parent, a personal support worker or an educational assistant. Over time through using the YouthKIT an individual may have different mentors that assist in facilitating completion of modules. For example, a special needs worker might understand the young person's social goals and relationships, but not feel comfortable facilitating completing the "transition to high school" module, which might be best handled by an educational assistant. One of the key characteristics of mentors is a belief in the potential of the young person to make decisions about their own future and achieve their own goals with appropriate supports. Regardless of the ability level of the youth, the mentor needs to support completion of worksheets by asking prompting questions rather than filling out answers for the youth. In this way, over time the youth takes control of their own information and planning for the future.

Building a Circle of Support

Families can consider starting up a “Circle of Support” for their youth, if they have not already started a “Circle of Friends” when their child was younger.

A life with friends, and purpose, a life that benefits one’s self and others, is the goal of parents for all their children. One way to work toward this goal is to build a Circle of Support around the young person in the family and ideally, to do so before s/he finishes high school. A Circle is an intentional gathering of people who would like to stay actively connected with the son or daughter with Down syndrome, hopefully for many years, and possibly their entire life span.

The creation of a Circle acknowledges that we all need the support of other people to help us live good lives and that when we give of ourselves in this way, we get back so much more. It doesn’t really matter if a Circle begins with three people or thirteen, as long as the people involved have made a commitment to the youth and family.

It is important to have the youth’s peers in the Circle. The young person should have complete involvement with who to invite into the Circle. The long-range goal is to have parents withdraw over time and have people much younger take on the commitment to keep the Circle active and alive.

Some people feel that there is nobody they could ask to be involved. This may be because the family or person has just moved to a new area or because they have become isolated over a period of time. Families shouldn’t give up on this, however. They can talk about this with a family member or friend. Just letting people know about family difficulties and wishes often provides new avenues of support. A Circle of Support is truly a “gift that keeps on giving;” it is a positive approach that builds the capacity of everyone in a family and community.

Parent Navigation

Parents of youth with Down syndrome also go through a transition and need supports at times. They can connect with existing parent support networks, as they often have resources about transition to adulthood, and also they may be able to connect the family





with a “parent navigator” which has been a recommended strategy for transition supports in the community (Stewart et al., 2009).

Parent navigators are community members, usually parents of youth with disabilities, who guide and coach parents through the transition process (Stewart et al., 2009). An important aspect of parent navigation is that a navigator is independent of any agency or ‘special’ service and is seen as a member of the natural community (Stewart et al., 2013).

There is very little research yet about the process and outcomes of parent navigation. A recent pilot study demonstrated numerous benefits for parents in relation to addressing their individual needs to support in the community, increased knowledge and skills, and a greater sense of empowerment (Sherman, Khan, Freeman, Stewart & Burke-Gaffney, 2013). The key ingredient in parent navigation emerged as the trusting relationship that develops between parents and navigator.

These practical considerations for families of youth with Down syndrome are evidence-based and take a positive approach. All of these suggestions recognize the need for person and environment supports to be implemented together to build the capacity of everyone – not just the youth – to promote a successful transition to adult living. It is also important for families to consider for both formal and informal supports during this transition. The formal resources that are available to youth with disabilities, especially during the high

school years, can help to develop their capacity for self-determination and building the skills they will need for future adult roles, but it is important to recognize that these supports will end upon graduation from highschool, or ‘discharge’ from pediatric services. There is therefore a need for families to begin building informal supports in their everyday, natural community, as these will be the ones that are sustainable when their youth wants to continue to participate in community activities, such as work, social and leisure activities, as an adult. We believe that this type of positive developmental approach will promote successful adult transitions for youth with Down syndrome and other developmental disabilities.

