

Growing Up Ready: A Framework for Preparing Youth with Disabilities for Adult Life

Need

- Young people with disabilities are surviving into adulthood due to advances in medicine and technology. They expect to live productive, fulfilling lives.
- To do this, they must develop the life skills that are needed in the adult world. However, during childhood and adolescence they are often deprived of everyday opportunities and life experiences as a result of institutional, social and environmental barriers (Antle et al., 1999; Bell & Quintal, 1983; Steele et al., 1996; Stewart et al., 2001; White 1997).
- Adults with disabilities experience above average rates of un/underemployment and poverty, as well as poorer overall health status (Government of Canada, 2004; McDonagh, 2006). Related outcomes such as higher utilization of health care resources have been documented (Young et al., 2009).
- Health and wellness are more than the absence of disease or disability. Organizations that serve children and youth with disabilities have an ethical responsibility to support youth in "growing up ready".

Background & Goal

- Bloorview Kids Rehab has traditionally offered some services to help youth prepare for adulthood, such as life skills clubs. The various services were not coordinated and referrals were inconsistent. Many Bloorview clients did not access any of these supports.
- Bloorview established a goal of developing an evidence-based, auditable framework that ensures that all youth and families have access to comprehensive supports to help youth grow up ready for adult life (Gill, Kingsnorth & Henly, in press).
- The development process for the framework included a thorough investigation of international best practice in transition services. Key elements of best practice are highlighted in the principles and design of the Growing Up Ready Framework.

The Growing Up Ready Framework

- The vision statement reflects a **shared responsibility** for preparing for adult life. "We" includes youth, families and service providers. The statement also highlights the importance of having **positive expectations** for the future.
- There is a **developmental sequence** to life skills acquisition. The framework encourages families and youth to **start early** to prepare for adult life. Some elements are applicable right from birth (e.g., Timetable for Growing Up). By starting early, youth can gain the skills they need gradually.
- The framework incorporates an **individualized planning** and **youth/family-centred** approach. Youth and families use the elements that they feel will assist them in preparing for the future. They may access elements as **developmentally appropriate** at different times throughout childhood and adolescence.
- The elements of the framework are **comprehensive**, including practical, written materials targeted to youth and families (e.g., Timetable, Checklists), as well as a variety of services.
- The framework is supported by two enablers: Systems Action & Capacity Building, and Organizational Commitment.

Bloorview KIDS REHAB Life Skills & Wellness Institute

Growing Up Ready Framework

Vision:
Together we have hopes and dreams for the future and we prepare for meaningful participation in life



Framework Guiding Principles

- We respect that the family is the expert on raising their child.
- We respect that each child and family is unique.
- We believe that it is essential that youth and families start early to prepare for the future.
- We plan a systematic approach to a gradual shift in responsibility from provider and parents to the young person as developmentally appropriate. (A shared management approach, as described by Kieckhefer & Trahan, 2000.)
- We all share responsibility for discussing and promoting the development of growing up skills (this includes families, youth and staff).
- We are committed to ensuring that all youth and families receive support for growing up ready. We adjust how our systems work to make sure that this goal is achieved. The systems that allow us to meet this goal may be different across various programs.
- We exchange information with colleagues around the world to ensure that our programs are at the leading edge.
- We believe that research and evaluation are vital parts of our work.

Development & Roll Out Strategies

- Input from a variety of stakeholders shaped the framework, including youth, parents, clinicians, academics, researchers, and funders. Listening to personal perspectives resulted in major modifications to elements of the framework.
- Strong organizational commitment contributes urgency and resources.
- The framework supports all youth (it is not disability-specific) but it is being implemented with programs/teams individually so that it can be customized appropriately and successfully integrated into practice.
- Champions are identified within each program/team to raise awareness of the issues and stimulate practice change.

Evaluation

- Each element of the framework has an evaluation process. Evaluation may include:
 - Perceived usefulness of materials and services
 - Self-reported change in abilities, knowledge, and/or satisfaction
 - Implementation costs
- When fully implemented, the framework will be auditable. We will be able to demonstrate that all clients received information about preparing for adult life and had the opportunity to access supports.

Framework Elements: Tools & Resources

- Timetable for Growing Up**
- Triggers conversation and action about planning for adulthood
 - Poster & pamphlet versions
- Developing the Skills for Growing Up Checklists**
- Guide youth & families in identifying priorities and making action plans for skill development
 - Series of 3 checklists, based on developmental stages

Framework Elements: Life Skills & Wellness Services

- Family Facilitators & Youth Facilitator**
- Provide peer-to-peer support and advice
 - Paid staff positions filled by parents of youth with disabilities or youth with disabilities
- Resource Sharing & Outreach**
- Promote health, well-being, active living and community participation of youth with disabilities by sharing resources and expertise
- Recreation Services**
- Provide opportunities to participate in leisure-related programs to have fun, build self-confidence and gain skills
- Experience-based Life Skills Programs**
- Facilitate learning life skills through hands-on experiences and calculated risk-taking
- Transfer Services**
- Help youth prepare to move smoothly from pediatric services to adult services
 - Planned/delivered in collaboration with adult service providers

Framework Enablers

- Organizational Commitment**
- Recognize the importance of preparing youth for adult life and provide resources to address it (including staff education)
 - Create a culture of openness to change
- Systems Action & Capacity Building**
- Research and evaluate
 - Network with national and international colleagues to share best practices and evidence
 - Collaborate with pediatric and adult service agencies and communities

