

Developmental Pediatrics

Title: GROWING UP READY: A FRAMEWORK FOR PREPARING YOUTH WITH DISABILITIES TO TRANSITION TO ADULTHOOD

Presenting Author: Julia L'Abbe, Bloorview Kids Rehabilitation

Background: Preparing for transition to adulthood is not intuitive. For countless families raising a child with a disability, the demands of everyday life often take precedence over future planning. Because of missed opportunities, many youth with disabilities lag behind their peers in developing the life skills necessary to successfully manage the adult world. A well-planned service is essential to help youth with disabilities “grow up ready”.

The Life Skills & Wellness Institute at Bloorview Kids Rehab has developed an evidenced-based, comprehensive and auditable framework to support youth with disabilities in growing up ready to participate fully in adult life. The framework recognizes the central role of families in the growing up process.

Method: The development process involved: (1) scan of best practices (literature reviews, site visits, collaboration with experts, youth and families); and (2) pilot testing components with selected clinical teams.

Results: Bloorview's Growing Up Ready framework uses the Shared Management Model (Kieckhefer & Trahms, 2000) as a philosophical foundation. Service providers, families and youth work together to gradually shift responsibility for daily life activities and decisions to the youth as developmentally appropriate.

The framework includes five key components. (1) Education for service providers about incorporating the shared management approach into daily practice. (2) Collaboration to enhance organizational systems ensuring that all youth have access to transition planning information/activities. (3) Development of transition tools and resources for youth, families and staff. (4) Recruitment of paid family and youth facilitators to enable parent-to-parent and youth-to-youth support for transition issues. (5) Ongoing provision of experiential life skill services to foster developmentally appropriate skill building.

Conclusion: Evaluation methodologies have been implemented for all components and will be shared.