

TOOLKIT FOR TRANSITION TO ADULTHOOD FOR INDIVIDUALS WITH TRISOMY 21

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Objectives

To design a toolkit for individuals with Trisomy 21 (Down syndrome) and their families that would assist with the process of transition to adulthood. A secondary objective of the project was to disseminate this information through a free, interactive community event.

Background

The transition to adulthood for individuals with Trisomy 21 can be a complex, confusing, and stressful time period for both the young adult and their family; for some, "transition feels like a free-fall instead of a bridge" (Simons, 2004). During this time there is a shift in support systems, a new emphasis on vocation and living arrangements, and a new medical team. Though transition is more successful when the young adult is involved, this rarely occurs for individuals with neurodevelopmental disabilities, or it may happen too late (Hetherington et al, 2010). Clinicians also play a large role in transition and are encouraged to help their patients by taking a broader, interdisciplinary approach to ensure that social, educational, and vocational plans are in place to support physical and mental health (Baumer, 2014). A comprehensive resource is needed to help families partner with clinicians, involve the young adult with Trisomy 21, and stay organized during a potentially stressful experience.

Methods

Needs assessment was conducted through informal interviews at the Trisomy 21 clinic at the Children's Hospital of Philadelphia (CHOP) to determine what areas of transition families would be most interested in learning more about. The areas that the toolkit primarily address include building independence, finding adult health providers, forming transition goals, and legal and financial information. Other areas discussed in the toolkit are health literacy, self-advocacy, and personalized resources. Feedback from parents and individuals with Trisomy 21 was incorporated throughout toolkit development.

Results and Conclusion

The toolkit, consisting of fourteen worksheets, was successfully produced and approved by CHOP Patient Education. The free community education event occurred on April 26, 2017. Eighteen parents/guardians and seven young adults with Trisomy 21 were in attendance, in addition to a LEND faculty member, two LEND fellows, and two mentors. Evaluation of the efficacy of the intervention was completed by participants; the event was rated 4.88 on a scale of 1 to 5, with 5 being the most helpful. Families expressed great appreciation of the toolkit and reported that they will likely continue to use the worksheets for guidance through the transition process. Future directions include making the toolkit available for any family to access and download from the CHOP website.

Worksheet Examples and Event Photographs

