

**Title:**

A Group Education Intervention for Improving Transition Readiness for Caregivers of Adolescents With Cerebral Palsy

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**Session Title:**

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**Slot:**

I 14: Monday, 30 October 2017: 3:45 PM-4:30 PM

**Scheduled Time:**

3:45 PM

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**Keywords:**

Anticipatory Guidance Model, Caregiver Transition Readiness and Pediatric Chronic Illness

**References:**

American Academy of Pediatrics (2015). Clinical Report: Transition. Retrieved from [www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-children-with-Disabilities/pages/policy-resources.aspx](http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-children-with-Disabilities/pages/policy-resources.aspx)

Betz, C. L., Ferris, M. E., Woodward, J. F., Okumura, M. J., Jan, S. & Wood, D. L. (2014). The health care transition research consortium health care transition model: a framework for research and practice. *Journal of Pediatric Rehabilitative Medicine*, 7, 3-15. doi: 10.3233/PRM-140277

Björquist, E., Nordmark, E., Hallström, I. (2014). Living in transition – experiences of health and well-being and the needs of adolescents with cerebral palsy. *Child: Care, Health and Development*, 41(2), 1365- 2214. doi: 10.1111/cch.12151

Blackman, J. A., & Conaway, M. R. (2014). Adolescents With Cerebral Palsy Transitioning to Adult Health Care Services. *Clinical Pediatrics*, 53(4), 356-363. doi: 10.1177/0009922813510203

Cerebral Palsy Foundation. (2015). *Definition of Cerebral Palsy*. Retrieved from [www.cerebralpalsy.org](http://www.cerebralpalsy.org)

Christensen, D., VanNaarden Braun, K., Doernberg, N. S., Maenner, M. J., & Arneson, C. L. (2014). Prevalence of Cerebral Palsy, co-occurring Autism Spectrum Disorder's and motor functioning-Autism and Developmental Disabilities Monitoring Network, USA, 2008. *Developmental Medical Neurology*, 56(1), 59-65. doi: 10.1111/dmcn.12268

Critical Appraisal Skills Programme (CASP). (2014). CASP Checklists. Oxford. CASP. Retrieved from [www.casp-uk.net](http://www.casp-uk.net)

DiFazio, R. L., Harris, M., Vessey, J. A., Glader, L., & Shanske, S. (2014). Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare. *Journal of Pediatric Rehabilitative Medicine*, 7, 17-31. doi:10.3233/PRM-140276

Dosman, C. & Andrews, D. (2012). Anticipatory guidance for cognitive and social-emotional development: birth to five years. *Paediatric and Child Health, 17*(2), 75-80.

East Tennessee State University. (2014). Department of pediatrics: Transition readiness assessment questionnaire. Downloaded with permission from David Wood, M.D. from <http://www.etsu.edu/com/pediatrics/traq>

Franz, S., McMahon, P. M., Calongne, L., & Steele-Moses, S. K. (2014). Anticipatory guidance through DVD. *Clinical Pediatrics, 53*(3), 256-260. doi:10.1177/0009922813520069

Got Transition. (2015). *Side-by-side version: six core elements of health care transition 2.0*. Retrieved from <http://www.gottransition.org/resourceGet.cfm?id=206>

Guillamon, N., Nieto, R., Pousada, M., Redolar, D., Munoz, E., Hernandez, E., Gomez-Zuniga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal of Clinical Nursing, 22*, 1579-1590. doi: 10.1111/jocn.12124

Larivière-Bastien, D., Bell, E., Majnemer, A., Shevell, M., & Racine, E. (2013, June). Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems. In *Seminars in pediatric neurology, 20*(2), 154-159. doi: 10.1016/j.spea.2013.06.009

Losby, J. & Wetmore, A. (2012). Using Likert scales in evaluation survey work. [www.cdc.gov/dhdsp/pubs/docs/cb\\_february\\_14\\_2012.pdf](http://www.cdc.gov/dhdsp/pubs/docs/cb_february_14_2012.pdf)

Pousada, M., Guillamon, N., Hernandez-Eneuentra, E., Munoz, E., Redolar, D., Boixados, M., & Gomez-Zuniga, B. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: a systematic review of the literature. *Journal of Developmental and Physical Disabilities, 25*, 545-577. doi: 10.1007/s10882-013-9332-6

Schwartz, L. A., Lauren, D., Brumley, L. D., Barakat, L. P., Wesley, K. M., &

Tuchman, L. K. (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: a systematic review and recommendations for measurement testing and development. *Journal of Pediatric Psychology, 1*-14. doi: 10:1093/jpepsy/jsuo28

experimental studies. *American Journal Health System Pharm, 58*, 2173-2181.

Stiefel, M. & Nolan, K. (2012). *A Guide to Measuring the Triple Aim: Population Health, Experience of Care, and Per Capita Cost*. IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement (downloaded from [www.ihl.org](http://www.ihl.org)).

Stinson, J., Ahola Kohut, S., Spiegel, L., White, M., Gill, N., Colbourne, G., Sigurdson, S., Watanabe Duffy, K., Tucker, L., Stringer, E., Hazel, B., Hochman, J., Reiss, J., & Kaufman, M. (2013). A systematic review of transition readiness and transfer satisfaction measures in adolescents with chronic illness. *International Journal of Adolescent Medical Health, 26*(2), 159-174. doi: 10.1515/ijamh-2013-0512

U.S. Department of Health and Human Services Centers for Disease Control and Prevention. (2011). *Introduction to program evaluation for public health programs: A self-study guide*. (pp. 1-41). Retrieved from <http://www.cdc.gov/eval/guide/CDCEvalManual.pdf>

Wood D.L., Sawicki, G. S., Miller, D., Smotherman, C., Lukens-Bull, K., Livingwood, W. C., Ferris, M., & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics, 14*(4), 415-422. doi:10.1016/j.acap.2014.033.008

**Abstract Summary:**

There is a critical need for a seamless transition process from pediatric to adult healthcare for adolescents with CP and other chronic pediatric conditions and their caregivers. This quality improvement project improved transition readiness for these caregivers through a group education intervention.

**Learning Activity:**

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
<p>The learner will be able to determine the effectiveness of the group education intervention for improving transition readiness for caregivers of adolescents with cerebral palsy.</p>	<p>The Iowa Model of Evidence-Based Practice to Promote Quality Care guided the development of this project. Using the Iowa Model, current best available evidence and expert guidelines were selected to guide development of the education intervention. The education intervention was designed using an evidence-based anticipatory guidance model. A family nurse practitioner, social worker, and vocational rehabilitation therapist facilitated presentations on key transition topics for CGs in a single session. Outcomes demonstrated improvement in transition readiness of CGs.</p>
<p>The learner will be able to understand how to use transition readiness measures to identify and improve caregiver transition readiness.</p>	<p>The Transition Readiness Assessment Questionnaire (TRAQ) was used to assess changes in transition readiness pre and post implementation of the education intervention and one-month post intervention. Process measure outcomes were developed for this project to assess the CGs’ response to the intervention, change in transition readiness and personal use of the educational materials.</p>

**Abstract Text:**

**Background**

The lifespan for children with Cerebral Palsy (CP) has dramatically increased, turning a once childhood disorder into a chronic adult condition. This has created a critical need for a seamless transition process from pediatric to adult healthcare for adolescents with CP and their caregivers (CGs). There are many barriers to a seamless transition of care that can result in severely negative outcomes for patients with CP and their CGs. A needs assessment in 2014 and process analysis in 2015 of the CP Clinics at a large urban specialty hospital revealed no formal transition readiness programs for CGs. This quality improvement (QI) project was developed to improve transition readiness for CGs of adolescents with CP.

**Methods**

The Iowa Model of Evidence-Based Practice to Promote Quality Care guided the development of this project. The specific aim of this QI project was to improve transition readiness for CGs of patients with CP at the CP clinics via an education intervention based on the identified needs of CGs for transition readiness. Using the Iowa Model, current best available evidence and expert guidelines were selected to guide development of the education intervention. The education intervention was designed using an evidence-based anticipatory guidance model. A family nurse practitioner, social worker, and vocational rehabilitation therapist facilitated presentations on key transition topics for CGs in a single session. Opportunities were provided for CGs to be active participants throughout the education intervention. The Transition Readiness Assessment Questionnaire (TRAQ) was used to assess changes in transition readiness pre and post implementation of the education intervention and one-month post intervention. Process measure outcomes were developed for this project to assess the CGs' response to the intervention, change in transition readiness and personal use of the educational materials.

## Results

Outcomes demonstrated improvement in transition readiness of CGs. The TRAQ questionnaire mean score improved from pre-test 4.44 to post-test one 4.60 and post-test two 4.83. On the process measure Likert scale question measuring transition readiness on a scale from 1 to 5, with 5 indicating the most improved, the mean score improved from pre-test 3.43 to post-test one 4.43 and post-test two 4.50.

## Conclusions

This QI project demonstrated that CGs of adolescents with CP transitioning from pediatric to adult healthcare participating in a group education intervention improved transition readiness on different measures. Furthermore, this improvement sustained when measured one month later. The project provided a successful intervention that can be included in the current transition program at this specialty hospital, and can be used to both monitor transition readiness and include CGs as collaborators in the process. The current education intervention can also serve as a model to improve transition readiness for CGs of children with other chronic conditions at large, urban specialty hospitals.