



Research Paper

“Thrust into adulthood”: Transition experiences of young adults with cerebral palsy

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Abstract

Background: The transition to adulthood, the gradual change in roles and responsibilities, is identified as a challenging time for adolescents and young adults with physical disabilities, including those with cerebral palsy. Health care, education, employment, independent living, and community engagement have been identified as areas of concern. However, relatively little research has been done to understand the experiences, perceptions, and needs of individuals with cerebral palsy as they transition toward adulthood.

Objective: The objective of this study was to explore the transition experiences, perceptions, and needs of young adults with cerebral palsy living in one state in the southeastern United States.

Methods: Focus groups with nine young adults with cerebral palsy (19–34 years) were conducted. The focus group interview explored the preparation for transition and experiences navigating adulthood. The audio-recorded groups were transcribed and analyzed using thematic analysis.

Results: Young adults with cerebral palsy identified numerous challenges associated with navigating adulthood. The main themes were: 1) being thrust into adulthood; 2) navigating systems and services; 3) understanding and managing my body; and 4) dealing with stereotypes and prejudice.

Conclusions: The findings highlight the need for a holistic approach to transition with a focus on building capacity and empowerment. To navigate complex systems of care, “navigators” or “facilitators” are needed. Additionally, practitioners and service providers in adult systems need further education about cerebral palsy. © 2016 Elsevier Inc. All rights reserved.

Keywords: Transition; Cerebral palsy; Adulthood

Transition is defined as a process of gradual adoption of new roles and the modification of existing roles.¹ One of the many transitions that occur over the life course is the transition from adolescence to adulthood.¹ During this time, adolescents typically become more independent and take on increased responsibility with regards to education, employment, health care, and community living. The transition to adulthood can be challenging for youth with special health care needs and physical disabilities, such as cerebral palsy.

Cerebral palsy (CP) is a group of lifelong, chronic, non-progressive motor disorders. Currently, over 90% of individuals with CP live past 18 years of age² and 80% live to

be over 30 years of age.³ This increased lifespan has illuminated the need for lifelong services and supports to enable individuals with CP to participate in adult life and maintain health. Between the ages of 16 and 21, most individuals with CP transition from pediatric health care and educational systems to adult systems. Research has shown that this transition, for most adolescents and young adults, is far from gradual or smooth. In the area of health care transition, identified barriers include pediatric practitioners' reluctance to “let go” and unfamiliarity with adolescents' concerns, adult care practitioners' limited training and knowledge regarding CP, and parents' reluctance to relinquish their involvement and decision-making role.^{2,4,5} While transition services are often fragmented, there is growing interest in considering transition as a comprehensive and collaborative process.⁶ To develop such a transition process, it is important to understand the perspectives of various stakeholders, including professionals, family members, and individuals with CP.

Little is known about the transition needs and experience from the perspective of individuals with CP. Stewart et al.⁷

Disclosures: This study was funded by the Gabriella E. Molnar-Swofford Pediatric Transitional Care Research Grant, Foundation for Physical Medicine and Rehabilitation.

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and Lariviere-Bastien et al.^{8,9} included young adults with CP in their investigations of the transition experience of youth with physical disabilities in Canada while Björquist et al.¹⁰ explored the transition needs of adolescents with CP in Sweden. These studies highlight the lack of continuity and coordination of services and the institutional, environmental, and social barriers that limit opportunities. These studies also illuminate the need for supports and the development of self-advocacy skills among young adults with special health care needs. While these findings are important, it is not clear whether these experiences and perceptions have cross-cultural implications. Different cultures have vastly different educational, health care, and social service systems. Therefore, it is important to explore the experiences of individuals with CP living in different regions of the world so that culturally appropriate transition services can be developed. The purpose of this study is to explore the transition experiences, perceptions, and needs of individuals with CP living in the southeastern United States.

Method

This study is a descriptive qualitative study.¹¹ We used focus groups as our data collection method to learn more about the transition experiences, perceptions, and needs of individuals with CP. Krueger¹² described focus groups as “carefully planned discussions designed to obtain perceptions on a defined area of interest in a permissive and nonthreatening environment.” Focus groups provide an environment for participants to discuss perceptions, opinions, and thoughts¹³ and can be useful for testing assumptions that go into the design of services.¹⁴

As part of a series for stakeholders, we held two focus groups for young adults with CP so they could provide their perspectives on the transition to adulthood. We strove to have a homogeneous sample but with sufficient variation among participants to allow for different experiences and opinions.¹⁵ Following ethics approval by the university Institutional Review Board, participants were recruited using personal contacts, an existing data base, flyers distributed through service agencies (e.g., Easter Seals United

Cerebral Palsy), and a letter distributed through a physical medicine and rehabilitation clinic for individuals with CP. The inclusion criteria were a self-reported diagnosis of CP and an ability to communicate at a conversational level (verbally or using an alternative communication system). Individuals with CP who had graduated from high school and were no older than 35 years old were invited to participate in the young adult focus groups.

Two groups, comprised of a total of nine adults, were held. Each group lasted approximately 100 min. Table 1 shows participant demographic information. Participants included four males and five females ranging in age from 19 to 33. All of the participants were unmarried and all were Caucasian, except for one who identified as multi-racial. All of the participants lived in one state in the southeastern United States; two lived in urban areas (population of 50,000 or more), three were from suburban areas (at least 2500 people but less than 50,000), and four lived in a rural area (areas with less than 2500 people).¹⁶ Four participants were unemployed, three were employed, and two were students. Five participants lived with family and four lived in their own apartment. Gross Motor Function Classification System- Expanded and Revised (GMFCS – E & R)¹⁷ levels, determined by the 4th author, ranged from I (individual is able to walk and run though balance and coordination are limited) to V (individual is transported in a wheelchair; limited antigravity control and leg and arm movements). A caregiver transported most of the participants to the focus group; however, caregivers did not participate in or listen to the focus groups. Participant confidentiality was preserved through the use of pseudonyms in place of names.

Members of the research team developed a focus group guide. The first author (NB), who had training in and experience leading focus groups was the moderator of both focus groups. Other members of the research team took notes and assisted participants as needed. Each focus group began with introductions. The first question focused on future goals (“What are some future goals that you have thought about for yourself?”). A card sort activity was then used to generate personal reflection and discussion about transition to adult life. Each participant was given index

Table 1
Participants' demographic information.

Participant pseudonym	Age	Gender	Highest level of education	Employment situation	GMFCS level	Community of residence	Living situation
Katrina	19	Female	Some college	Student	I	Suburban	With family
Dan	21	Male	High school	Unemployed	V	Rural	With family
Neal	22	Male	Bachelor's	Unemployed	I	Suburban	With family
Allison	23	Female	Some college	Student	IV	Rural	With family
Amy	25	Female	Bachelor's	Employed	I	Urban	Own apt
Kelly	30	Female	Bachelor's	Employed	I	Urban	Own apt
Karen	31	Female	Master's	Employed	IV	Suburban	Own apt
John	32	Male	Bachelor's	Unemployed	V	Rural	With family
Michael	33	Male	Some college	Unemployed	II	Rural	Own apt

Abbreviation: GMFCS: Gross motor functional classification system.

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