

**Exploring the Experience of Transitioning from Pediatric to Adult Healthcare Systems from the Perspective of Individuals with Disabilities**

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Evidence table:

<b>Author/Year</b>	<b>Purpose</b>	<b>Research Design</b>	<b>Methods</b>	<b>Outcomes</b>
White et. al., (2013) <sup>1</sup>	Update guide to, identification of, and recommendations for improved transitioning from pediatric to adult healthcare for SHCN	Clinical report	Research statements from professional societies published since original clinical report of 2011 was synthesized	Sections of the original clinical report were updated to reflect more practice-bed guidance on transition planning, transfer of care, and transition processes
Oswald et. al., (2013) <sup>2</sup>	Define and identify factors associated with successful transition from pediatric to adult health care services for CYSHCN	Systematic review	Follow-up SATH interview with 1,865 young adults who had participated in an original survey in 2001 and were then between 14-17 years old	21.6% of YSHCN successfully transitioned to adult health care
Watson et. al., (2011) <sup>3</sup>	Identify models of successful transitioning from pediatric to adult healthcare for CHNs	Systematic review	19 papers regarding transition care for CHNs published between 1980 and 2010	Study concludes there is a lack of evidence to support best practice in both the process and what qualifies as effectiveness of transitional care for CHNs
Reiss et. al., (2005) <sup>4</sup>	Examine barriers and facilitators of successful HCT and report on experiences of YHCN and their families	Qualitative study	34 focus groups were conducted for 3 groups (143 youth and young adults with disabilities and SHCNs, family members, and healthcare providers)	Trust in relationships between families and healthcare providers, lack of transition preparation, and differences in subcultures of pediatric and adult healthcare medical models emerge as important factors for

				how HCT is experienced by YSHCN and their families
Bloom et. al., (2012) <sup>5</sup>	Look at outcomes of YSCHN who do not undergo transition interventions and identify strategies that lead to better healthcare outcomes such as access to adult healthcare	Systematic review	15 articles of 3,370 published from 1986-2010 were reviewed by 2 primary researchers with a third investigator resolving any disagreements	Gaps in transition experiences were reported, as well as variables impacting how successful transition processes may be
McKenzie et. al., (2019) <sup>6</sup>	To assess: 1) transition preparedness of YSHCN, 2) individual factors associated with transition preparedness, and 3) medical home components associated with transition preparedness	Cross-sectional analysis	Responses of 17,114 parents of YSCHN (ages 12-18 years) to the 2009-2010 NS-CSHN were analyzed using weighted descriptive, bivariate and multivariate analyses	Overall, 32.1% of YSHCN were adequately prepared for transitioning
Bagatell et. al., (2017) <sup>7</sup>	Explore perceptions, needs and experiences of young adults with CP who underwent transitions from pediatric healthcare systems to adult ones	Descriptive qualitative study	2 focus groups (for a total of 9 adult participants with CP) were held for approximately 100 minutes each	Four main themes related to challenges experienced by young adults with CP emerged: 1) sudden transition to adulthood, 2) systems and services navigation, 3) managing of one's own body, and 4) handling prejudices/stereotyping
van Staa & Sattoe (2014) <sup>8</sup>	Examine experiences and satisfaction of young adults with chronic health conditions with transition from	Cohort study	Follow-up pilot-tested 2012 survey with 518 young adults (18-25 years old) respondents with chronic health conditions	Of the 65% of respondents that transferred from pediatric to adult healthcare, 20% felt transfer was unsatisfactory and 50% felt prepared for

	pediatric to adult healthcare		to a Web-based 2006 survey	transition. Ten percent were still in a pediatric system and 25% were receiving no care at all
Scal & Ireland (2005) <sup>9</sup>	Determine factors associated with transitioning from pediatric to adult-centered healthcare in the USA for adolescents with SHCN	Analysis of NS-CSHCN	Analysis of parental responses to items on the 2000-2001 NS-CSHCN to determine whether or not HCT services for their adolescents with SHCN were adequate	50.2% of parents reported having discussed transition care with doctors of their adolescents, while 16.4% had discussed/developed a transition care plan
Burke et. al., (2008) <sup>10</sup>	Understand transition and transfer of care of adolescents from pediatric to adult healthcare from the perspective of primary care physicians	Survey report	All primary care physicians in Rhode Island were surveyed	60.9% of pediatricians responded and of those 13% reported having written policies in place on the transition and transfer of adolescents to adult care
Orlin et. al., (2014) <sup>11</sup>	Describe specific challenges youth with particular LLDs face during the transition to adult healthcare and suggest ways PTs can assist in healthcare transitioning	Descriptive qualitative study	Described demographics of individuals with developmental LLDs, factors involved in their life-span health care needs and access to care, implications for PT role in transitions, and potential solutions to current transition barriers	Two of the biggest barriers to transition of youth with LLDs to adult-centered care were the inability of child-centered health care providers to 'let go' of their patients and their distrust of adult-centered health services
Betz et. al., (2013) <sup>12</sup>	Evaluate research about healthcare transitioning from the perspective of AEA-SHCNs	Systematic review	35 studies were reviewed after meeting inclusion/exclusion criteria following a search of 3 databases for publications since 2005	Transitioning of healthcare for AEA-SHCNs is a complex issue with the desire for these individuals to be an integral part of the process at the heart of it

Bhawra et. al., (2016) <sup>13</sup>	Explore ways in which primary care provider involvement can be improved during the transition process from pediatric to adult healthcare for youth with chronic conditions	Systematic review	1,888 citations were screened by 2 reviewers leaving 3 left to discuss based on Triple Aim Framework (i.e., experience of care, population health, and cost) domain approach	Cost domain was the most commonly reported outcome in determining effective primary care professional interventions with respect to transitioning youth with chronic conditions
Okumura et. al., (2013) <sup>14</sup>	Study variables associated with health status and access to care for adults with special health care needs after transitioning to adulthood	Descriptive longitudinal analysis	Responses of 1,865 adults (19-23 years old) whose parents completed the 2001 SATH then completed the 2007 follow-up SATH were analyzed	Factors associated with worsening health status reported by 10.6% or respondents included disease severity, delayed or lack of care, and interruptions or changes in insurance coverage
Rhem et. al., (2012) <sup>15</sup>	Determine priorities and goals of YSHCN and DDs and their parents during transition to adulthood	Interpretive field study	Ethnographic methods were used to report data collected from interviews and informal observations of 64 YSHCN and their parents	Four priorities emerged that all encompassed a desire for creating safe environments for YSHCN that promote high quality of life in their adulthood
Chu et. al., (2015) <sup>16</sup>	Examine evidence about the effectiveness of transition programs for AYA going from pediatric to adult health care systems	Systematic review	5 articles out of 6,167 yielded and 106 reviewed at full text level were reviewed	Three out of 5 studies associated higher rates of successful transference of care with patient participation in transition program
Acharya et. al., (2017) <sup>17</sup>	Explore transition outcomes and disparities in youth with disabilities as they relate to 6 “F-word” domains (i.e., function, family, fitness,	Descriptive qualitative study	Literature review	Less than half of transition-aged youth with disabilities receive adequate transition planning and many experience disparities in all 6 “F-word” domains

	fun, friends and future)			
McManus et. al., (2013) <sup>18</sup>	Examine status of healthcare transition of SCHCN in the USA and suggest strategies for improvement	Survey report	Random sampling of parents or legal guardians of CSHCN who completed the 2009-2010 NS-CSHCN resulted in 17,114 interviews	Overall, 40% of YSHCN met national transition outcome with disparities based on gender, race/ethnicity, household language, socioeconomic status, insurance status, and severity/type of health condition
Cohen et. al., (2011) <sup>19</sup>	Define a framework for healthcare needs, healthcare utilizations, and characteristic chronic conditions and associated functional limitations for children who are medically complex	Descriptive analysis and agenda proposal	Development of a definitional framework, based on systematic reviews of clinical and research initiatives and reported health/resource needs of those with chronic diseases arising in childhood	Presentation of a model definitional framework that uses specific chronic conditions, functional limitations, healthcare utilization, and patterns of needs to describe children with medical complexities

Abbreviations:

CP- cerebral palsy

NS-CSHCN- National Survey of Children with Special Health Care Needs

SHCN- Special health care needs

CYSHCN- children and youth with special health care needs

SATH- Survey of Adult Transition and Health

CHN- children with special health care needs

HCT- health care transition

CP- cerebral palsy

LLD- lifelong disabilities

PT- physical therapy

AEA-SHCN- adults and emerging adults with special health care needs

AHSN- adults with special health care needs

DD- developmental disabilities

AYA- adolescents and young adults

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