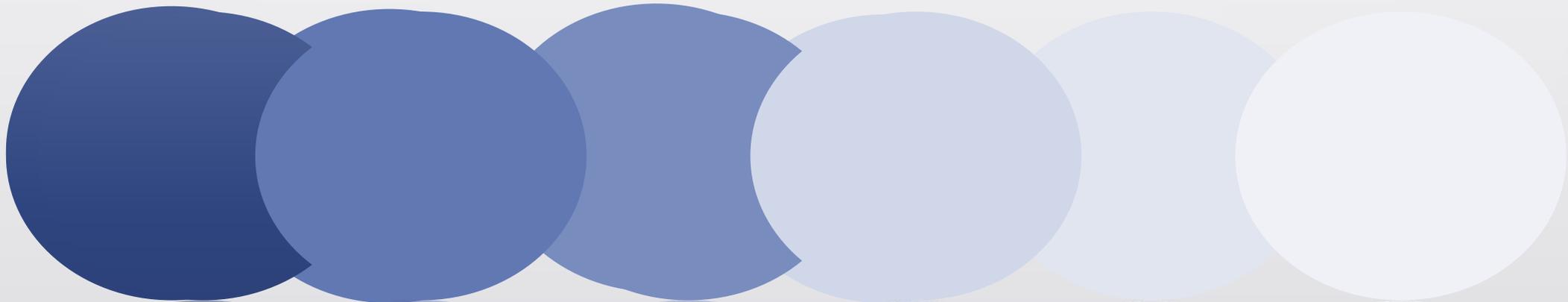




Perspectives in Health Care Transition



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Glossary of Terms

Term	Definition
Health Care Transition, HCT	Period of transition in health care among youth and young adults from pediatric to adult health care providers.
Youth with Chronic or Special Health Care Needs (YCSHCN)	A general term in health care literature referring to youth and young adults with either chronic and/or special health care needs which may include youth and young adults with disabilities.
Youth/Young Adults with Intellectual and/or Developmental Disabilities (IDD)	Refers to a population among youth or young adults with disabilities with an intellectual or developmental disability, or both.
Health Care Disparities (health care inequities outside of the U.S.)	<ul style="list-style-type: none">• "population-specific difference[s] in the presence of disease, health outcomes, or access to care" (Health Resources and Service Administration, as cited in Carter-Pokras & Baquet, 2002)• "...disparities in health and in its key demographic, social, economic, and political determinants that are systematically associated with social advantage/disadvantage" (Ouellette-Kuntz et al., 2005).



Health Care Transition: A National Focus

- Health care transition has been received considerable attention over the past few years as several federal initiatives developed to improve health care access and utilization.
- The Maternal and Child Health Bureau has prioritized transition as one of the primary core health outcomes. It has recently partnered with the National Alliance to Advance Adolescent Health to develop strategies and programs to improve transition such as the Got Transition™ initiative.

<http://gottransition.org/resourceGet.cfm?id=206>

- The American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians have also partnered to develop several transition strategies including educational resources, guides and toolkits for providers.



Health Care Transition: The State of Florida



- In 2008, during the legislative sessions, Florida called for a statewide taskforce to specifically address health care transition which included the development of regional coalitions and strategies to promote and ensure health care transition.
- Florida's Department of Health and Children's Medical Services (CMS) have coordinated a mission to secure and improve health care transition for youth and young adults.
- These populations include YSHCN, youth and young adults with disabilities.
- Florida HATS is the procurer of several planning guides, tools and resources for providers, individuals and families.





Research Findings: What does the literature tell us?

- Despite these efforts, disparities continue to exist.
- Research has shown that individuals with IDD are the most underserved among populations of individuals
- Research tells us the disparities are significant during the transition period from pediatric to adult care.
- A great deal of research has been conducted on this subject using the published national survey data
- There has been little improvement in access and quality of health care services delivered for transitioning young adults with IDD over time
- Survey data has indicated the among young adults with IDD, those who belong to racial and ethnic minority populations have even greater disproportionalities in health.
- Cultural differences between providers and clients have also been suggested to have effects on communication, belief and understanding the family's cultural views on disabilities.



Disparities in health care for transitioning young adults with IDD

- Some of the themes found in the research relate to issues of ***access, quality, reimbursement/insurance issues, implicit bias/apprehension, continuity, knowledge/experience*** and ***competence***:
 - Low quality preventive care
 - A lack of developmentally appropriate care
 - Limited direct training and experience among providers
 - Stigma, inexperience and apprehension for treating individuals with IDD
 - Small numbers of providers and specialists willing to treat this population
 - Challenges in insurance coverage and service delivery during this transition period
 - Low reimbursement for services provided
 - Communication barriers
 - Lack of culturally and linguistically competent care



What is unique about this transition period?

The Life Course Framework:

Periods between stages of development are of particular significance as they are often marked by increased stress and multiple changes.

Transition periods require skill, competency and responsiveness to developmental needs among professionals (Turnbull et al. 2011)

Health Care Disparities Framework:

The effects of disparities in HCT on other factors of life

Challenges to addressing disparities in HCT as an outcome rather than a process

More policies have been aimed at addressing the health care needs of children but not young enough for young adults whose services and delivery of services change (Giarelli et al. 2008)



Perspectives in Health Care Transition: Stakeholders

Multiple stakeholders have perspectives on HCT. Some of these perspectives align while others do not. Each can provide some important information for policy and initiatives.

Example 1: “I had to go to the ER for an entire week for my son because no doctor would take him. It had nothing to do with his autism, it was for a chronic headache.”—Parent of Young Adult with Autism

Example 2: “It’s not that I don’t want to treat people with [IDD]. I just don’t feel competent. I don’t have the training and I feel unprepared, meanwhile they have been with their pediatrician for years.” –Adult Provider

Example 3: “Listen, I am just as invested in their health as anyone else. These are my clients. If they aren’t healthy, they cannot work or do anything else. That’s it.”—Agency representative

What research tells us

1. National Survey Data indicates there are disparities in HCT among young adults with IDD
2. Conflicting research findings among qualitative studies
3. Limited research telling us about the impact of these disparities on the lives of young adults with IDD
4. Limited inclusion of other stakeholders on this issue including agency support and community personnel
5. Additional barriers found among subgroups of transitioning young adults with IDD

What we need

1. Regional survey data to provide the landscape of this issue at a local level
2. Better assessment of contributing factors from the personal perspective.
3. Qualitative studies to provide insight on this issue and ascribe meaning; specific inclusion of young adults with IDD and their families
4. Perspectives of other stakeholders to expand insight and provide additional information
5. Design and implement studies to determine underlying cultural and linguistic barriers for dually marginalized young adults

How we can explore it

1. Conducting empirical studies at a regional and local level
2. Surveys; interviews and focus groups using purposive sampling, specific recruitment of self advocates, caregivers and parents
3. Surveys; interviews and focus groups using purposive sampling
4. Individual, families, providers, agency representatives and community personnel as key informants.
5. Inclusion of diverse cultural and linguistic participants in order to provide rich contextual detail



Specific Aims: A Collaborative Effort

- Using an interdisciplinary and collaborative effort, we have proposed a research study with multiple components:
- The following are the **specific aims** of the study:
 - 1. To quantitatively assess the status of health care transition among young adults regionally/locally via administration of surveys as aligned with the Got Transition! Goals
 - 2. To qualitatively assess the perspectives, experiences and impact of health care transition among young adults with IDD through the lens of multiple stakeholders:
 - Self-advocates, individuals with IDD
 - Parents and caregivers
 - Providers, practitioners
 - Agency representatives and community support personnel
 - 3. To integrate and publish our findings and disseminate this information to our key informants. This information serves not only as a needs assessment but to provide recommendations for policy and further research.

A Sample Study

"Some patients were referred to the emergency rooms because health practitioners were not trained or equipped to work with them." (Ward et al. 2010, p. 287)

Citation

Ward, R., Nichols, A., & Freedman, R. (2010). Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health & Social Work, 35*(4), 280-90.

What

A research study conducted in 2010 by Ward et al. which addressed the gaps in the current research about health care disparities. experienced by individuals with IDD.

Research Question

"Thus, the present study used focus groups with self-advocates, parents/guardians, and community support professionals and key informant interviews with health care professionals to assess the quality of health care services received by adults with ID/DD."

Availability and Snowball sampling

Recruitment:

18 Self-Advocates

41 Parents/Guardians

57 Community Support Professionals

Collaboration:

School of Social Work

ARC of Massachusetts

Methods:

Focus groups and Interviews

Analysis:

Grounded Theory (Strauss 1987)
Contextual Analysis (Charmaz 2006)

Findings:

Themes that emerged were grouped under access, knowledge gaps, lack of communication and quality issues,

Limitations:

Provider perspective?
Design of interview questions
Took place in a "medical mecca"
Unclear about contextual analysis
Vetting of recommendations/member check



Research Goals: Important Tenets

- Central to the research goal is how quality, comprehensive, developmentally appropriate, and continuous health care is accessed and received by young adults with intellectual and developmental disabilities.
- A lifespan approach is important, especially during this critical transition period. Transition as a process not an outcome.
- The quality and delivery of health care for transitioning young adults with IDD is perceived in many different ways by various stakeholders,
- The ways in which these stakeholders negotiate, receive or deliver healthcare access is moderated at the systems level, where the delivery of resources and education is determined.
- Studies have indicated barriers at the patient, pediatric and adult provider as well as the insurance systems levels (Hergengroeder et al. 2015)
- Due to the multiple levels involved in this model, it is important to disaggregate the key informants and gather their perspectives to obtain themes.



Individual and Family Focus: A Primary Step

SUMMARY:

1. A primary step is to assess the total impact of this issue on the self-advocate/young adults/individual with IDD and his/her family/caregiver.
2. Quantitative assessments (surveys) should be customized to address the specific concerns around transition reflected in the literature that directly affect the individual.
3. Interview guides for qualitative assessments should include the key informants (self-advocates and parents) in development.
4. Results and analysis should be vetted for contextual understanding and meaning (member checks).
5. Important to emphasize is that this is FOR the individuals and their families to improve their health and quality of life. All stakeholders, including providers and representatives have a professional interest and investment in this as well to improve the quality of what they do professionally. This is the primary purpose of the study and all of its publications.



Questions?

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Thank you for participating in this Webinar on

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