Introduction
- Adolescents and young adults with developmental disabilities have difficulties transitioning from pediatric to adult health care.
- "Health care transition is the purposeful and planned process moving from the pediatric to the adult health care system." (Blum, 2003)
- Research suggests that both families and health care providers face difficulties with the health care transition process. (Geenen et al., 2003)
  - Barriers for families and adolescents include finding knowledgeable adult providers, difficulty with managing one's own care, and lack of access to a service coordinator
  - Barriers for providers include a lack of training in developmental disabilities, a limited amount of time to focus on transition, and a lack of financial reimbursement for transition services

Study Objectives
- Gain more detailed information about the transition to adult healthcare by asking parents/caregivers of adolescents with developmental disabilities, a limited amount of time to focus on transition, and a lack of financial reimbursement for transition services

Method
- Participants in the Parent Focus Group were five parents of adolescents with developmental disabilities between the ages of 15-17 that included Autism Spectrum Disorder, Spina Bifida, Down Syndrome, and sickle cell, and transplant issues
- The researchers met and consensus-coded to reach agreement on final themes and subthemes

Results
- Themes from Parent/Caregiver Focus Group
  - Communication
    - "I hear you say a policy would be really instrumental. It's not just our [pediatric health care] policy. It sounds like they [adult health care] don't need a policy too. You really do need a system of care, a policy, and a role."
  - Care Coordination
    - "If you think about how we want the primary care doc to take more of this role (transition coordinator), they're not going to have that sort of resource. It's a really good resource to have. There's got to be institutional investment."

Discussion
- Both parents and providers mentioned an overall lack of knowledge regarding healthcare transition and what it encompasses for youth with developmental disabilities.
- Regarding all of the areas of transition for youth with developmental disabilities, healthcare transition did not seem to be the biggest priority for parents
- Parents and providers both communicated the need for greater collaboration among pediatric and adult healthcare providers, community agencies, and schools, as well as families
- There was a general consensus among parents and providers that there is a need for resources and easily accessible information regarding best practices for healthcare transition

Next Steps
- Additional focus groups should be conducted with larger, more diverse samples
- Specific supports for the healthcare transition process should be identified, developed, and made accessible to providers, adolescents, and their families
- Investigate the perspectives of adolescents with developmental disabilities on their own healthcare transition needs
- Explore the perspectives of school personnel regarding their knowledge of healthcare transition and the role they might play in supporting healthcare transition for adolescents

Selected References