

TransitionInAction Clinic: Integrating Health, Education & Employment

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Need Statement:

A mixed methods research study identified a need for education, tools, and information related to facilitating the transition from pediatric to adult health care for young adults with disabilities and significant medical needs to enhance health care access and outcomes and reduce health disparities.

Facilitating Transition:

TransitionInAction Clinic

This clinic was developed to address these needs and provide the means for a holistic transition experience. This innovative clinic is a comprehensive, daylong, multi-disciplinary team experience designed to assess an adolescent's current transition "status" and make recommendations in the following major life areas:

- health care
- employment
- wellness
- personal supports
- education
- independent living
- self-determination
- future planning

The clinic includes interviews, assessments, discussions, mini work experiences, and activities with medical, education, rehabilitation, independent living, and adult service personnel. A family member, self-advocate peer mentor, and sibling are an integral part of the clinic process.

Venue for Medical Education

Pediatric residents, LEND students and other trainees participate in the clinic as part of their educational program. In this program, students gain an understanding and awareness of the complexities of care and everyday realities for adolescents with chronic health conditions and disabilities. They also learn to:

- identify important assets of an adolescent during transition.
- assess youth's current practical experiences and skills in areas that demonstrate competency.
- assess current opportunities to develop and practice those assets.
- assess families' current connections in the adult health provider systems.

Tools:

Transition Engagement Guide

This conversational guide offers practitioners a series of talking points to facilitate discussion and action planning. It serves as a "current status check" of key aspects of successful transition. From this conversation, medical professionals, along with their patients, develop an "action plan" for addressing the skills and supports needed to enhance the adolescent's self-determined actions over time.

Doc Talk

This tool, developed by young adults with disabilities, provides a tool to assist with active participation in their medical appointments. This tool provides youth with a guide to start conversations with their medical provider.

"...has become a different person since the Transition Clinic. She's doing more on her own, just more independent- she seems older."

"...practiced asking questions by herself when at doctor's office."

"...report has become our Bible. We refer to it often."

"...realized it's OK to step back and let him be more independent."

Preliminary Outcomes:

Participants

- 14 youth ages 16 to 21
- Disability Labels: Autism, Down Syndrome, TBI, FASD, Deaf/Blind, & Intellectual Disability
- Co-occurring Mental Health, Health & Behavioral Issues

Metric: Got Transition

- The respondents who, prior to the Clinic, felt confident (10) about their "ability to prepare" for change to an adult doctor, went to feeling SIGNIFICANTLY LESS (3) prepared to do so six months after...
- The respondents who didn't feel at all [0] confident about their "ability to prepare" for a change jumped to feeling SIGNIFICANTLY MORE confident.

Metric: AIR Self-Determination Scale

- Pre-tests indicate youth "seldom" or "never" set goals, nor do they establish any systematic strategy for achieving tasks.
- Greatest challenge reported is making changes/adjustments in life.
- Post-tests show slight increases in self-determination and ability to make adjustments.

Metric: Transition Assessment and Goal Generator

- Pre-tests indicate that it is not uncommon for there to be a significant discrepancy between what the professional and parent/youth report with the professional responding much lower.
- Post-tests suggest overall improvement and significant jump by professionals with greatest increase in areas of persistence, interacting with others, and goal setting attainment.

Metric: Social Capital

- Anecdotal reporting suggests that social networks are expanding for the youth and parents.

Future Research:

- Adolescent Health Rotation-milestone performance data assessment
 - Next step: Application to other disciplines
- Transition Consult-study aimed at assessing intervention efficacy
 - Next step: Billing potential and expansion
- TransitionInAction Clinic-longitudinal study to evaluate impact and outcomes
 - Next step: Replication and scaling up

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