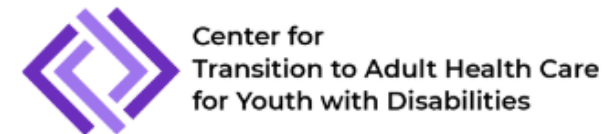


Facilitating Successful Health Care Transition for **Youth with IDD in the Juvenile Justice System**

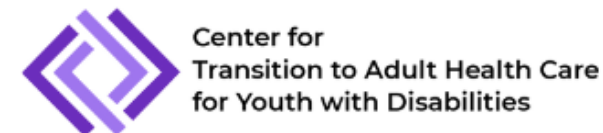
Josh Branch and Nikki Montgomery



About Our Work

The project entitled “Meeting the Health Care Transition Needs of Youth with Intellectual and Developmental Disabilities in the Juvenile Justice System” was funded through a grant from the WITH Foundation.

Family Voices partnered with The Arc’s National Center on Criminal Justice & Disability and the Center for Transition to Adult Health Care for Youth with Disabilities.



Objectives

- Understand the barriers to health care transition (HCT) for youth with intellectual and developmental disabilities (IDD)
- Learn about the HCT challenges, supports, and recommendations for youth with IDD who have been in the juvenile justice system

About the Center for Transition to Adult Health Care for Youth with Disabilities

A center funded by the Administration for Community Living led by Family Voices, in partnership with Got Transition, SPAN NJ, University of Missouri Kansas City, and the Waisman Center

- Includes a Youth Steering Committee that helps to guide the work
- Currently in year 3 of 5
- movingtoadulthealthcare.org

What We Know about HCT

- **Only 14%** youth with ID/DD received guidance from their health care providers about HCT.
- **Only 22%** of youth with IDD talked to their doctor about moving to an adult provider.
- **Only 38%** of youth with IDD had time alone with their doctor.
- Little is known about HCT for youth with IDD in the juvenile justice system. These youth are likely to experience intersectional barriers that impact the HCT process.

Barriers from Youth Steering Committee & Literature

- I am nervous about being an adult.
- My doctor only talks to my family and not to me.
- I do not have enough information about advocating for myself.
- I have not had time alone with my doctor without my parent or caregiver.
- I am not ready to leave my pediatrician.
- It is hard to find an adult doctor.
- No one explained how my health care would change when I become an adult.
- My doctor's office does not know how to handle my disabilities.

“Falling off a cliff...”

- Youth/young adults with ID/DD and families say most of transition work is left to them:
 - Building self-care skills
 - Navigating health services
 - Figuring out about supported decision-making
 - Finding a new adult doctor
 - Coordinating care plans

Health Care Transition and Juvenile Justice

Based on a project funded by the WITH Foundation

Where We Began

- An estimated **33% of youth and young adults** who are in detention have an intellectual or developmental disability (ID/DD) (Quinn et al., 2005).
- While in detention, they face **barriers to adequate care**, including inadequate health histories, lack of subspecialty care, and an insufficient number of providers (Perry & Morris, 2014).
- Upon release, follow-up of medical and psychological care is often neglected (Society for Adolescent Medicine, 2000) due to **lack of access to health insurance** (Golzari & Kuo, 2013) and primary care in their community (Feinstein et al., 1998).
- Youth and young adults who have been in detention are at **increased risk of poor health outcomes**, including shorter life expectancy and worse social functioning (Massoglia, 2008).
- 85% of youth and young adults who were previously in detention report **not seeing a health care provider** after release (Golzari & Kuo, 2013).

About the Project

Funded by the WITH Foundation

Meeting Health Care Transition (HCT) Needs of Youth with ID/DD Who Have Been in Detention

Project Goals

- Learn more about the HCT needs of youth and young adults with IDD who have been in detention facilities
- Engage these youth in leadership opportunities
- Develop educational resources for families and professionals
- Develop tools for youth to help them lead their own health care transition.

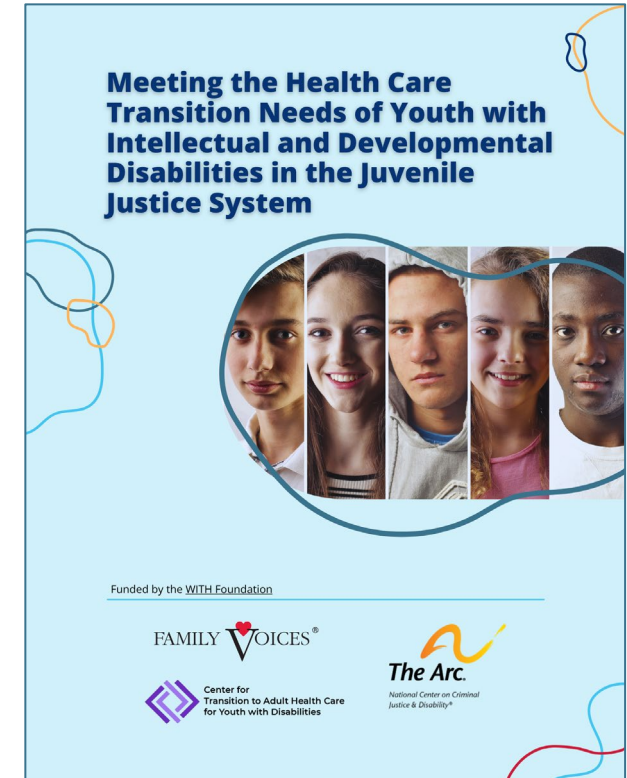
What We Did

Interviews and Surveys

We conducted key informant interviews and surveys to learn about the health care transition needs of youth with ID/DD in detention

- Youth and juvenile detention center staff

Info Brief



What We Learned

- Youth did not feel prepared to advocate for themselves as they transitioned to adult care.
- Many leaned heavily on the advocacy skills of their mothers.
- Youth typically had about 30 minutes to meet with health care staff but often had staff members present during medical appointments.
- Roughly 50 percent of staff stated they did not have procedures to screen for IDD.

What We Learned

Staff expressed frustration with HCT cited the following problems:

- Not having appropriate staff to be HCT or ADA coordinators.
- Youth losing their health care benefits (Medicaid) upon entry of facilities.
- Delay or disruption in critical health care services like mental health treatment or follow up appointments.
- Confusion in navigating different healthcare systems pediatric vs. adult.
- Reentry transition plans not including health care transition.

Recommendations

Youth and Families

- Ask about options for **health services** and health care in the detention facility.
- Ask about what you **qualify** for.
- Ask to work with a **care coordinator**.
- Visit **movingtoadulthealthcare.org** for tools to help you with health care transition.

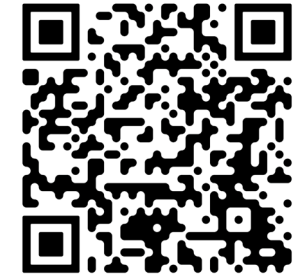
Health Care Providers

- Focus on **individualized services** that meet the specific needs of youth with IDD.
- Provide life skills **coaching and skill-building activities** for youth with IDD to manage their own care, with support from their families.
- Provide **adequate time** to share information with youth with IDD in a private setting.
- **Emphasize health care transition** and different health care systems a child may be transitioning to as they become an adult.

Recommendations

Juvenile Justice Professionals

- Help youth to **reinstate their Medicaid** benefits and/or SSI before they are released back into the community, when possible.
- Include **health care transition as a treatment goal** so the team can focus on connecting the youth with resources and partners once they leave the detention facility.
- Assign a long-term transitional coordinator (CYFD) and insurance care **coordinators**.
- Build **trusting relationships** with families to reduce their fear or concerns about engaging with juvenile justice staff after release.



Questions and Answers

Q&A

Web Resources

- MovingtoAdultHealthCare.org
- thearc.org/our-initiatives/criminal-justice
- familyvoices.org/HealthCareTransition/YouthinDetention
- GotTransition.org



Thank you.