Meeting the Health Care Transition Needs of Youth with Intellectual and Developmental Disabilities in the Juvenile Justice System

Funded by the WITH Foundation

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Center for
Transition to Adult Health Care
for Youth with Disabilities

The Arc.
National Center on Criminal
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Meeting Health Care Transition Needs of Youth with Intellectual and Developmental Disabilities in the Juvenile Justice System

Introduction

Health care transition (HCT) is the process of moving from a pediatric to an adult model of health care. Although an estimated 33% of youth and young adults who are in detention centers have an intellectual or developmental disability (IDD), little is known about their health care transition needs (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).

Once they leave juvenile detention facilities, youth with IDD often don't have access to health insurance (Golzari & Kuo, 2013) or primary care in their community (Feinstein et al., 1998). In fact, 85% of youth and young adults who were previously in detention report not seeing a health care provider after release (Golzari & Kuo, 2013). As a result, the follow-up for medical and psychological care they receive in the detention facility is often neglected (Society for Adolescent Medicine, 2000).

For all these reasons, youth and young adults with IDD who have been in detention are at increased risk of poor health outcomes, including shorter life expectancy and worse social functioning (Massoglia, 2008).

Family Voices and our core partners in the ACL-funded Center for Transition to Adult Health Care for Youth with Disabilities worked with The Arc's National Center on Criminal Justice and Disability to:

- Learn more about the intersectional needs of youth and young adults with intellectual and developmental disabilities who have been in juvenile detention facilities;
- Develop tools for youth to help them lead their own health care transition and engage in supported decision making and;
- Develop educational resources for families and professionals.

Download recommendations from this report

Methodology

In this grant-funded project, we conducted key informant interviews and surveys to learn about the health care transition needs of youth with IDD in detention. We recruited participants through Family Voices network of Family-to-Family Health Information Centers and Family Voices Affiliate Organizations, as well as through The Arc of the United States' National Center on Criminal Justice and Disabilities' network of affiliated organizations.

More about who we engaged in this project

Youth with IDD

We spoke to and/or surveyed seven young adults (18-26 years old) with intellectual and developmental disabilities who had experience in juvenile justice facilities. Some of the young adults completed a survey independently, while others completed it with assistance or answered the questions as part of a verbal discussion. These multiple methods of gathering information were intended to make the process accessible to young adults with IDD.

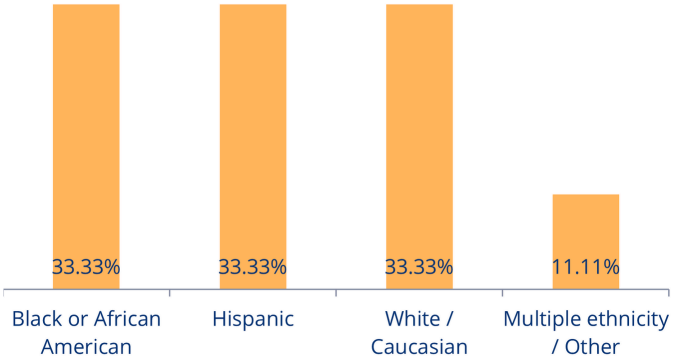
The young adults who provided the information for this project were all males who identified their race as either Black or African American (28.57%) or White (71.43%).

Their time spent in juvenile justice facilities ranged from less than two weeks to three months or more in the past five years for the young adult participants.

Juvenile Justice Professionals

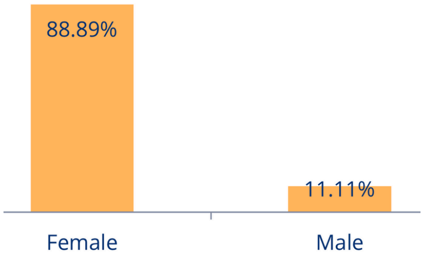
We spoke to and/or surveyed nine juvenile justice professionals, seven of whom had worked in a juvenile justice facility in the past five years. Some of the professionals completed a survey independently, while others answered the questions as part of a verbal discussion.

Race/ethnicity of juvenile justice professionals who participated



(multiple responses were allowed for this question)

Gender of juvenile justice professionals who participated



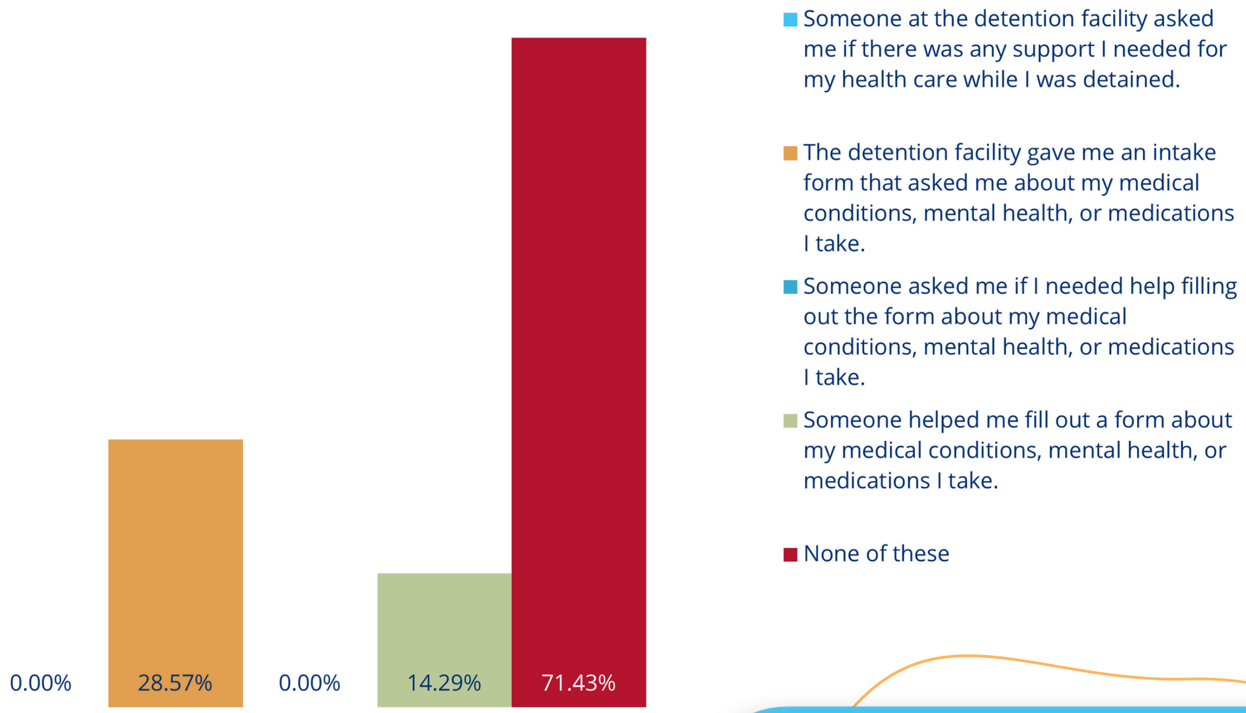
Youth Health Care Experiences in Juvenile Detention Centers

We asked seven young adults with IDD about:

- Access to health care services while in detention
- Their interactions with health care professionals in the juvenile detention facility
- Access to support in managing their health care needs
- How the transition to adult care was addressed in their health care experiences in the juvenile justice facility
- Health care transition services after they left the detention center

Health Care Information

The young adult participants answered the following questions about how their health care information was collected and used while in a juvenile justice facility.

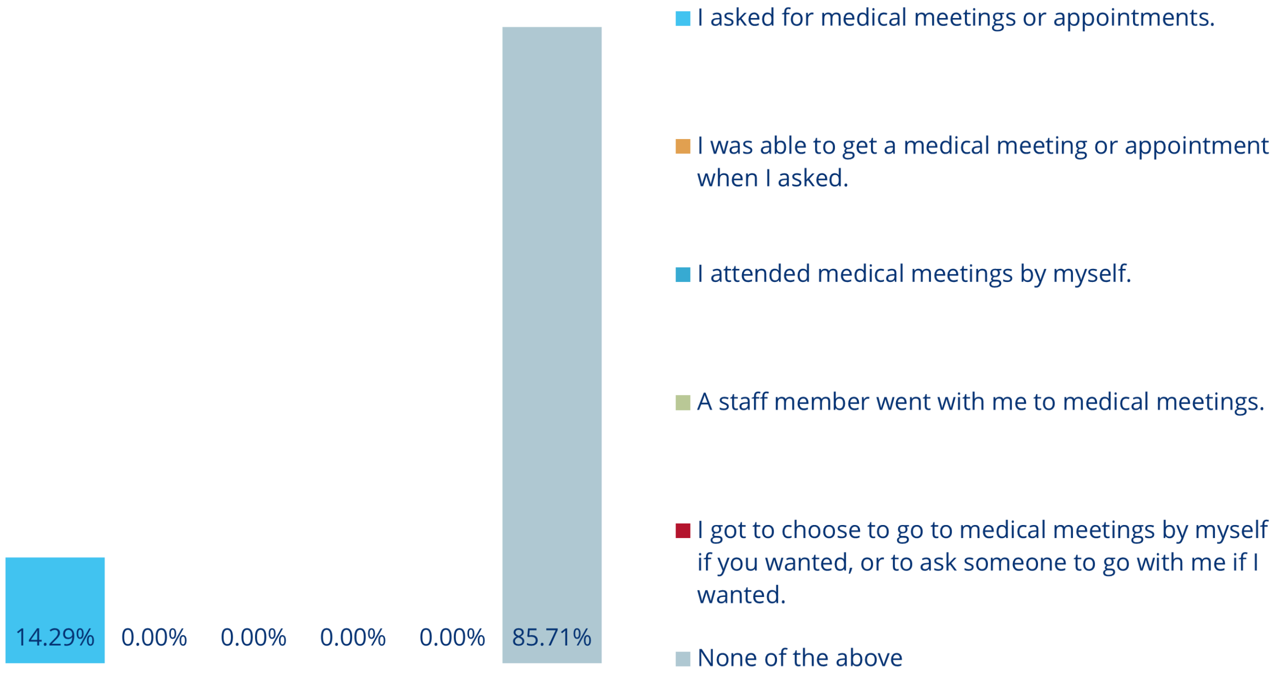


When asked "In what other ways did someone help you with your health care while you were in the detention center?" we heard, "**My mother talked to the nurse**."

Youth Health Care Experiences in Juvenile Detention Centers

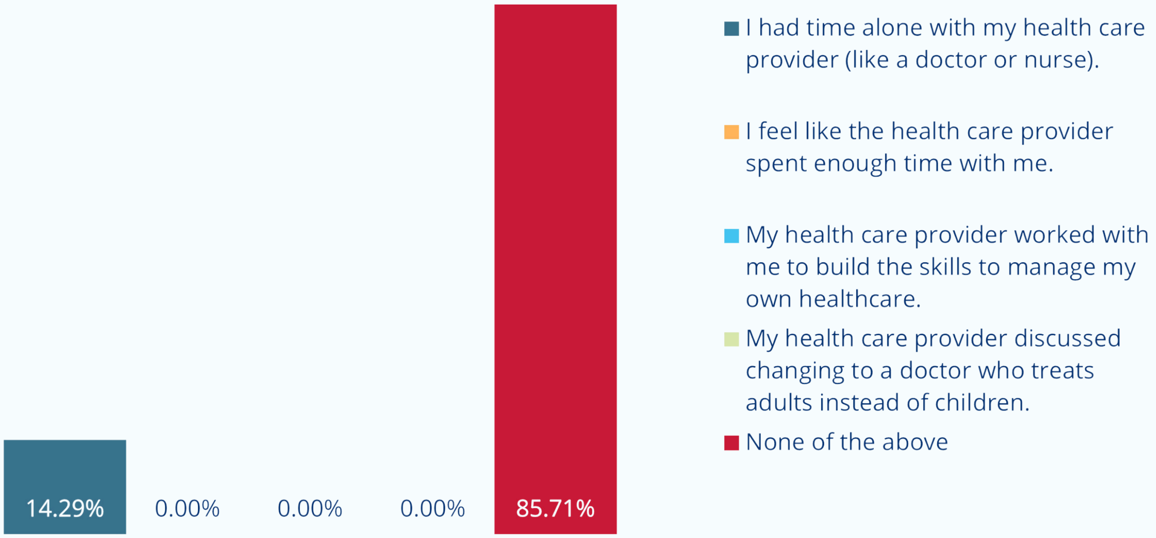
Access to Care and Supports

Of the youth who participated, only one had asked for a medical meeting or appointment while in a detention facility.



Activities of Health Care Transition

When asked about the key practices that indicate health care transition, only one of the participants had time alone with their health care provider.

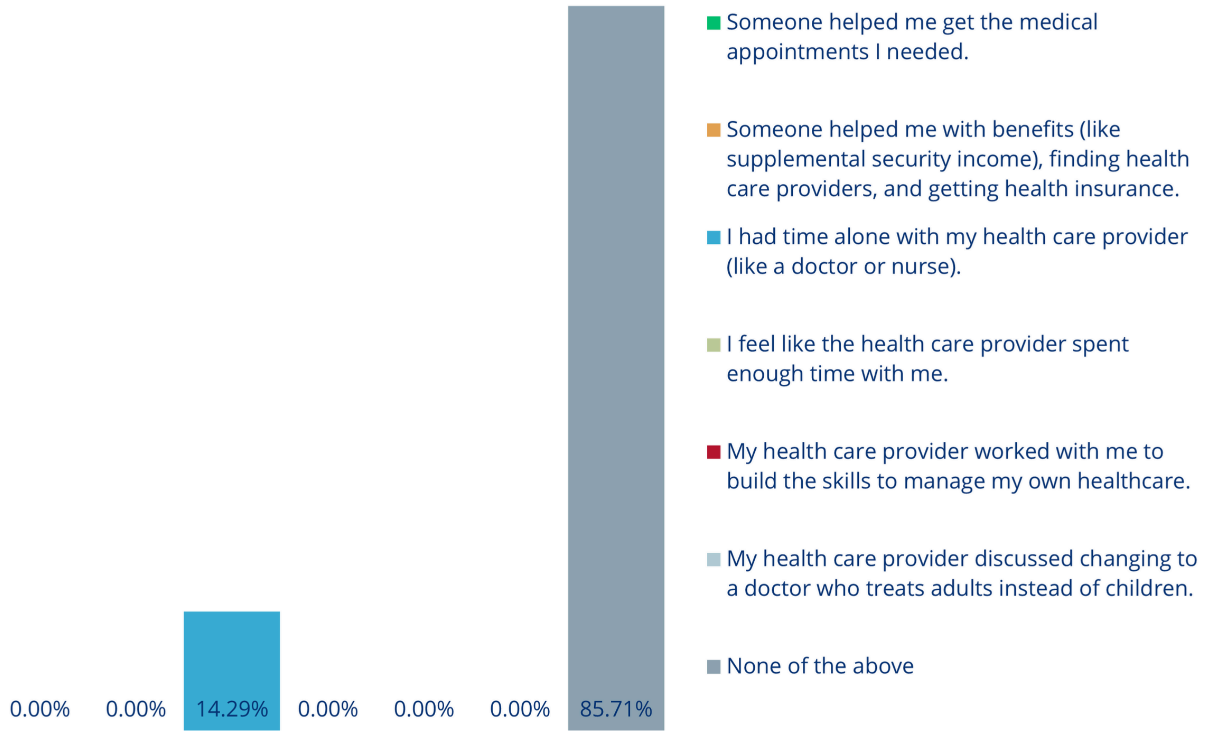


Youth Health Care Experiences in Juvenile Detention Centers

None of the participants experienced the following indicators of health care quality in the juvenile detention center.

- The health care provider asked if I had questions about my health care.
- I feel like the health care provider understood my health care needs.
- When the doctor, nurse or other healthcare provider talked to me, they spoke to me directly.
- When the doctor, nurse or other healthcare provider talked to me, they spoke to someone else (facility staff member, parent, guardian).

After Leaving the Juvenile Detention Center

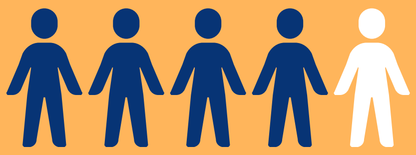


Youth Health Care Experiences in Juvenile Detention Centers

Learning Self-Advocacy Skills

When asked how they learned to speak up for their needs in the health care setting, the participants largely learned from their mothers, specifically (4 of 5 who responded to this question).

The support provided by mothers ranged from helping to make phone calls and attending appointments to encouraging self-advocacy in conversations. One other participant learned to call their local 211 site for mental health supports.

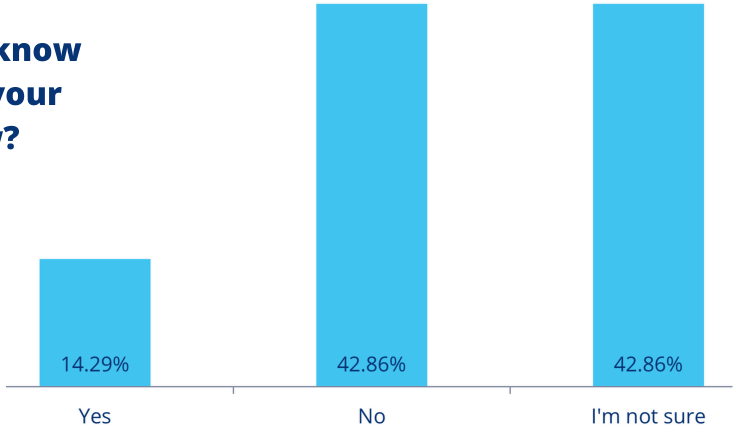


Four of the five young adults who shared where they learned their self-advocacy skills told us they learned those skills from their mothers.

Readiness for the Adult Health Care System

The young adults who participated largely did not have confidence in their ability to manage their care in the adult health care system.

Do you feel like you know how to take care of your own health care now?

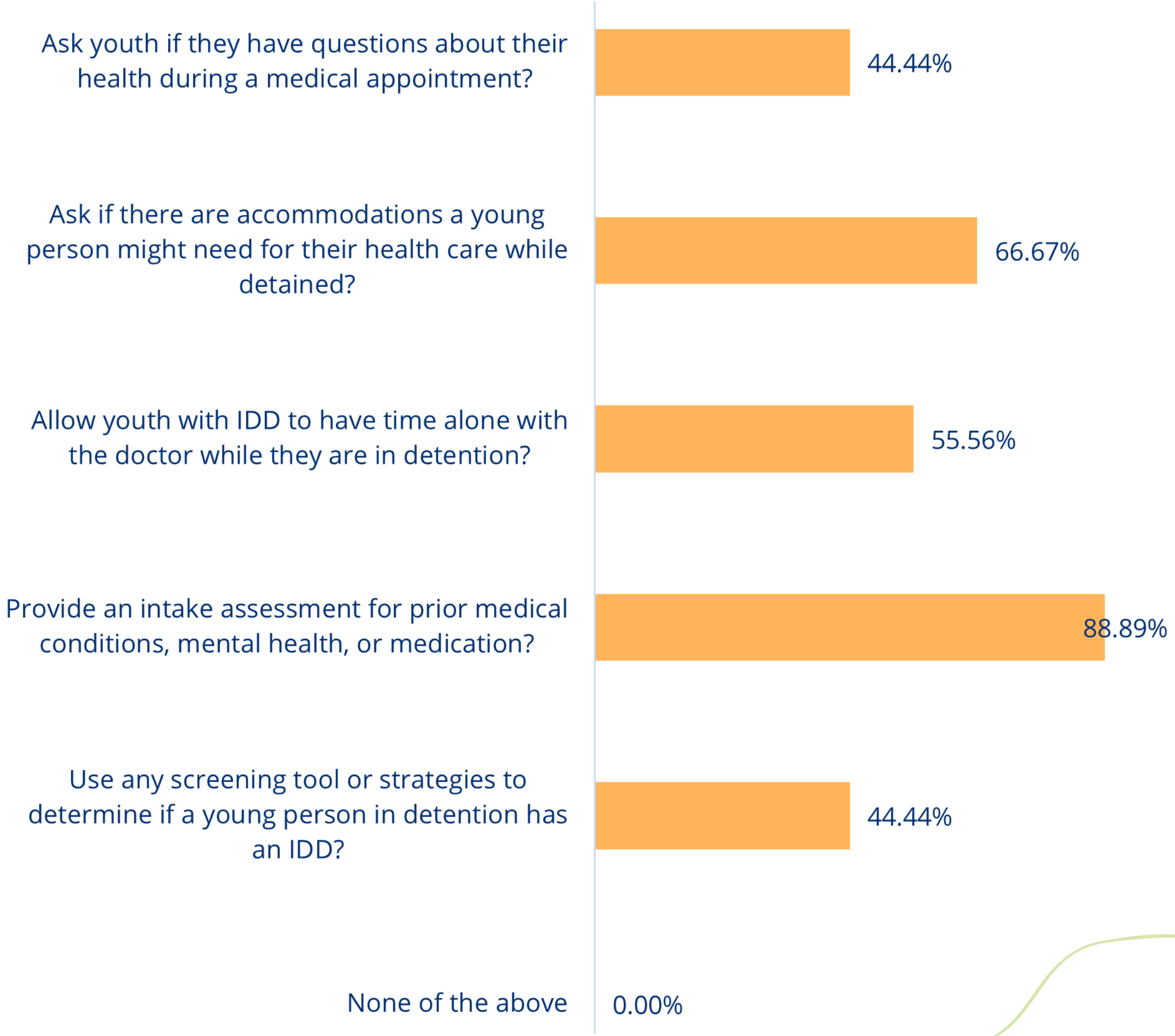


Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Juvenile justice professionals shared information about the health care services offered by the facilities where they had worked. They were asked to consider the facility where they had worked for the longest period of time in the past five years.

Health Care Services

Did/does the juvenile detention center where you work(ed):

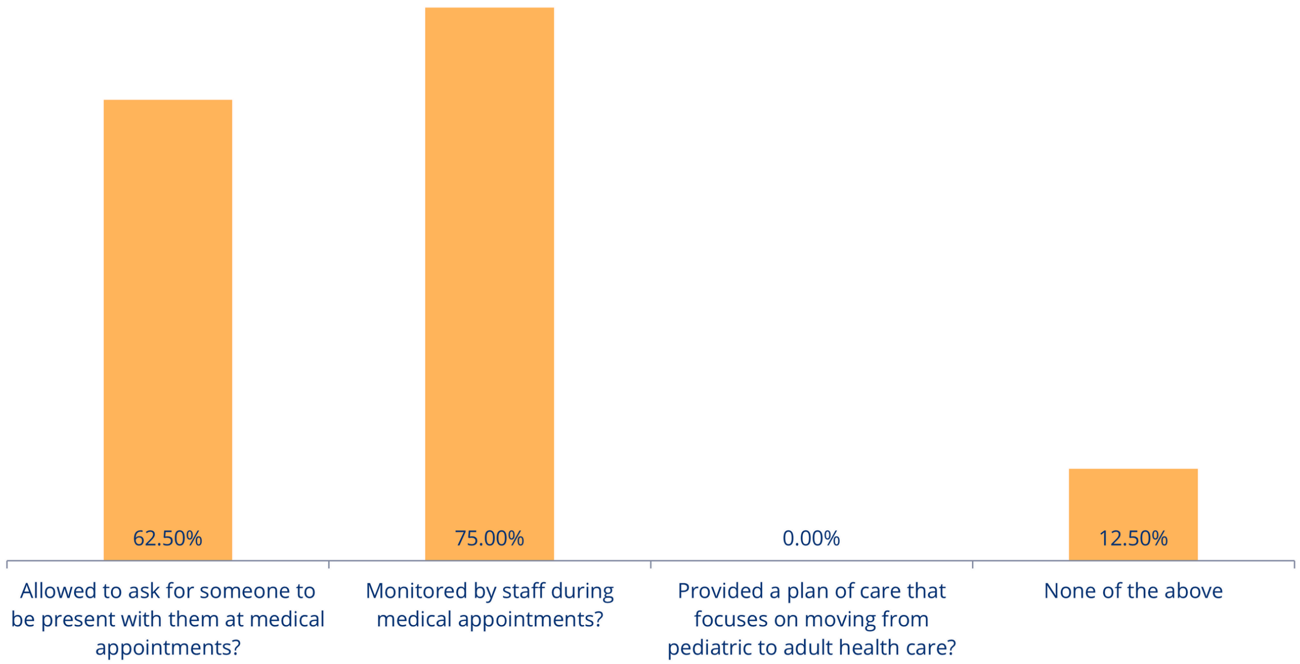


> American Correctional Association provides certification services [and] quality service reviews. [We] haven't been certified because they charge; we've been trying to maintain documentation to uphold standards.

Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

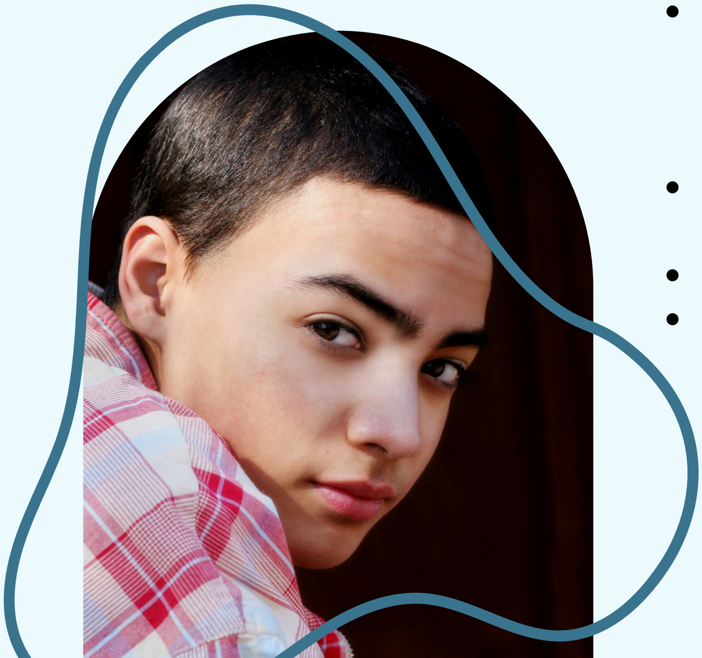
Access to Care and Supports

Were/are the youth at your facility:



How do youth request a medical appointment at your facility?

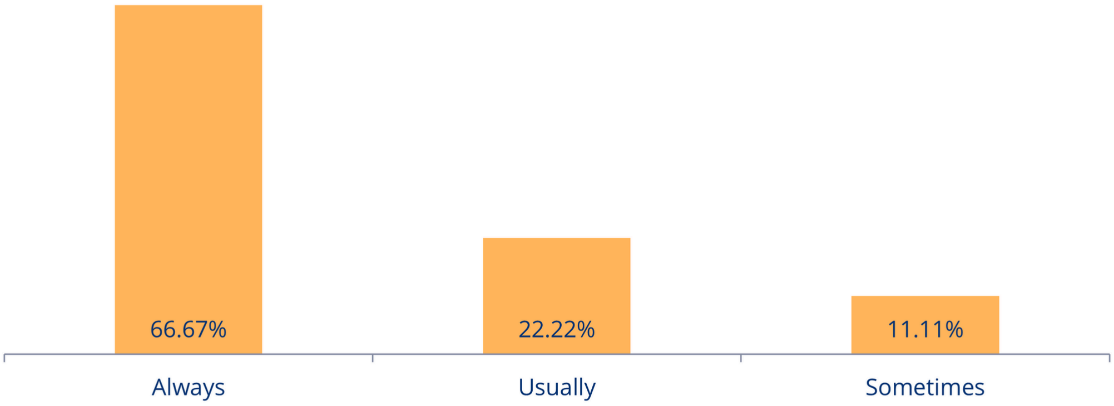
- They have a request form, and sometimes it takes months to get the care they desire.
- Residents can complete a physical sick call request, or inform any staff, teacher, parent, attorney, or caseworker of the medical request.
- Fill out medical request slip, or verbally for an urgent need.
- Talk to the doctor on call or nurse on site.
- The medical unit supports the appointment, as does the juvenile probation officer, in collaboration with the parent, etc.



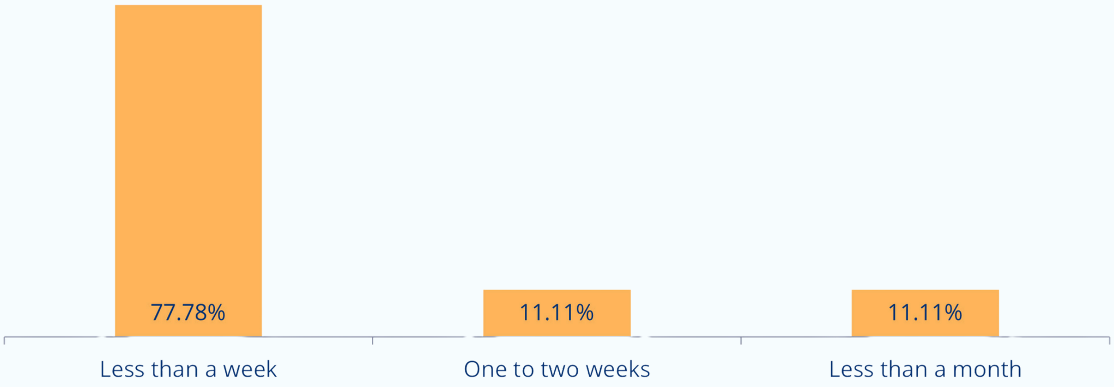
Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Access to Care and Supports

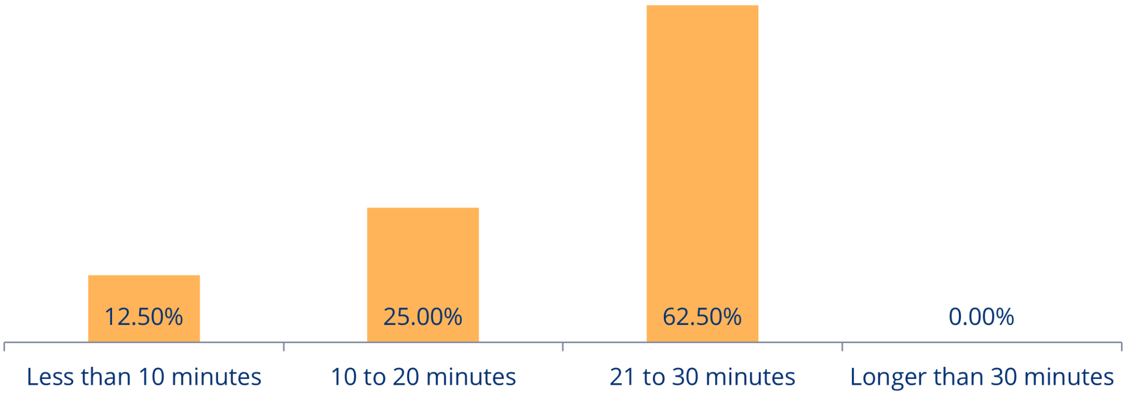
How often are youths' requests for medical appointments granted?



How long, on average, does it take for youth to get a medical appointment after they request one?



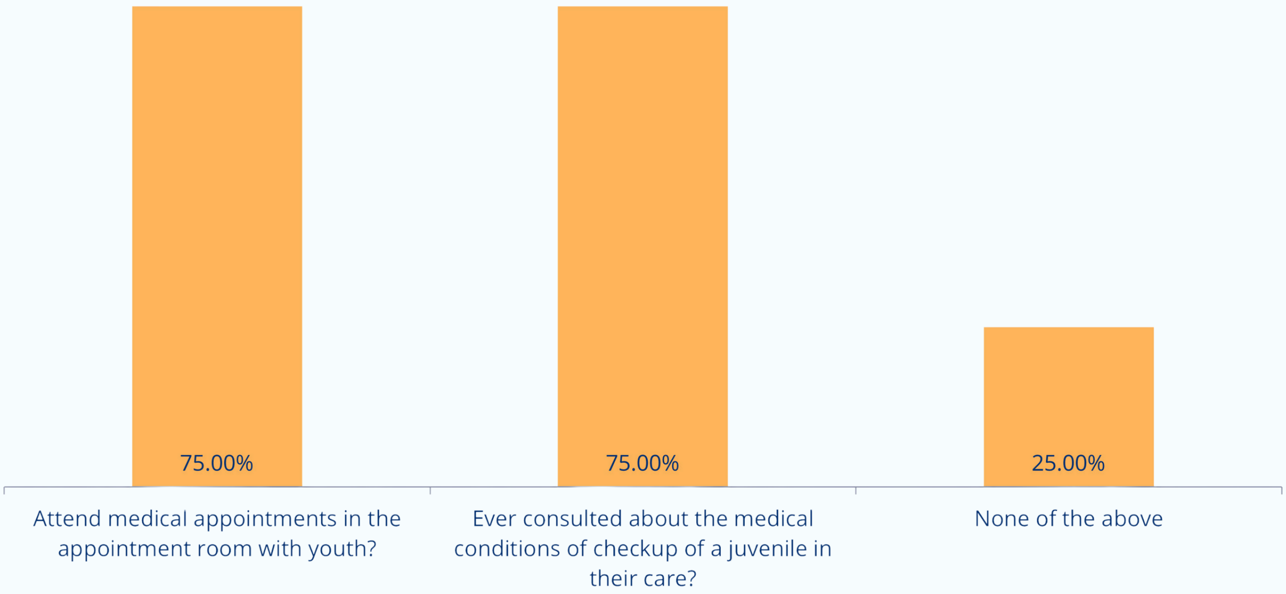
How long, on average, do youth spend with a medical provider?



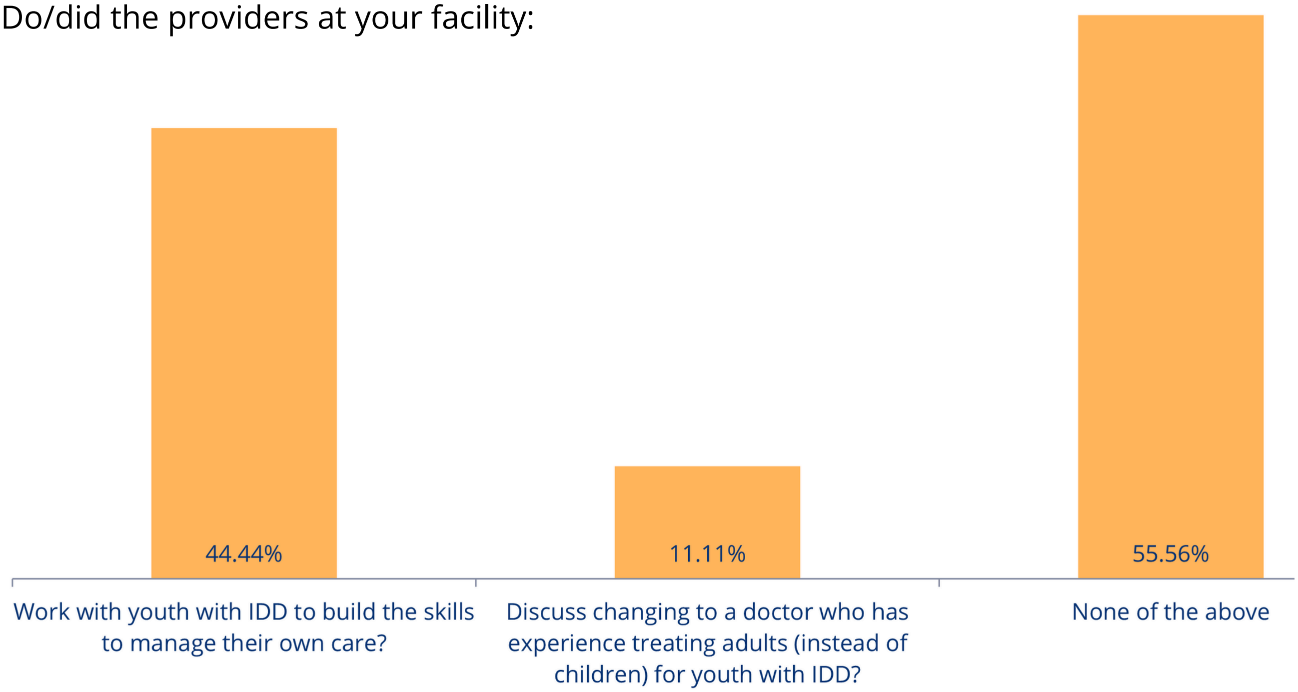
Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Access to Care and Supports

Do/did the staff at your facility:



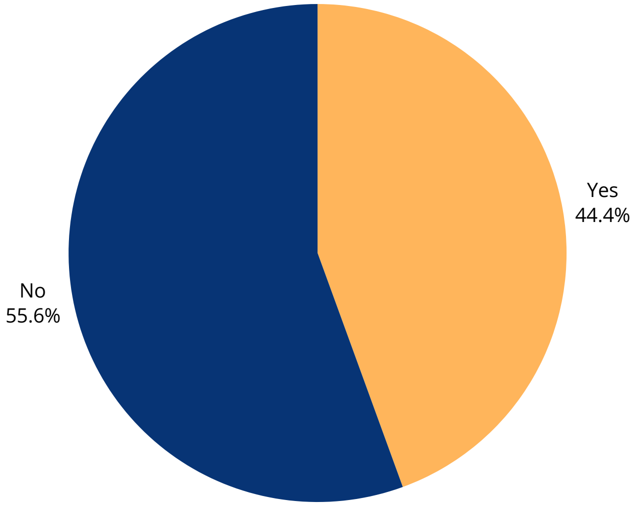
Do/did the providers at your facility:



Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

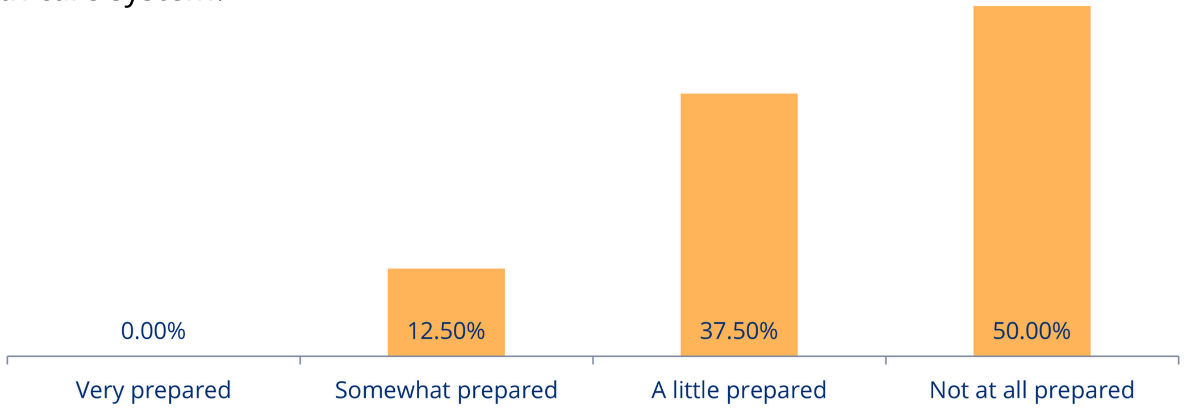
Readiness for the Adult Health Care System: Connecting Youth to Resources

Is there a focus on connecting youth with Supplemental Security Income (SSI), providers and health insurance resources for when they leave your facility?



> So many people lose SSI or Social Security Disability Insurance (SSDI) because they have no idea they are supposed to do a whole different process and switch when the youth turns 18, and they lose it for 9 to 12 months while they navigate to get that back.

How prepared do you feel youth with IDD are to manage their health in the adult health care system?



Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Readiness for the Adult Health Care System: Facilitation of Self-Advocacy Skills

Who in your facility helps youth prepare for the adult health care system?

- Case managers and social workers
- Transition care coordinators
- Mental health providers
- Nurses
- Parents and family members
- Programs from nonprofit organizations
- Detention center staff

What do detention center staff do to prepare youth for the adult health care system?

- If a need is identified, they are connected to social and behavioral services.
- Refer clients to life skills coach or Parent coach to help the parent, or refer them to mentors, etc.
- Give them a list of resources in their communities [and] help them apply for Medicaid benefits.
- Staff research, recommend and locate potential providers. We schedule consults and accompany residents as needed.
- Unsure

> While they are here with us, we can meet all their needs with healthcare, mental health, all that. But them having an advocate once they got out and into the community would help tremendously as far as someone to follow up with them to make sure they are getting the services they need.

> I think we need to include how we prepare residents with IDD for how to manage their healthcare in the adult health care system; that should be a treatment goal. If we have a 17-year-old turning 18, we can start connecting services and finding the right care providers, getting appointments.

Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Participants identified successes and challenges for youth with disabilities in accessing health care during their time in detention.

The Good

- Youth have always been able to access medical support.
- We have not faced challenges; we seek referrals from our treatment team and ensure we follow up as needed on an individual basis.

> "We just took a resident shopping for school clothes and school supplies because we've had her for 10 months so she isn't the same size she was when she left home. She needs to go into the school year with what she needs. We addressed all of this. We went shopping, met with mom, got school supply list. Made sure this wasn't something mom had to worry about.

The Bad

- Lack of needed resources, and/or extremely long wait for resources
- It is difficult for youth to identify what they need. Oftentimes accessing health care is reliant on the youth to identify needs or fill out slips.
- Navigating different systems adds an additional layer of confusion for families and this is often not communicated well to them.

> Basic medical check-up appointments are so far in advance, it is really hard to get an appointment. One of our [intellectually disabled] clients was told to go to the ER because the waitlist was so long they wouldn't be seen for 4 months. It isn't a matter of appointments being granted, but access to documentation and the laws through agencies and what they can take (liability)."

Juvenile Justice Professionals and Health Care at the Facilities Where They Worked

Participants identified successes and challenges for youth with disabilities in accessing health care during their time in detention.

The Ugly

- Youth are sometimes put on prescriptions that they don't like or don't agree with and are not always given a choice around what prescriptions they have to take. Sometimes they are also coerced to take a drug they feel uncomfortable with.
- Youth in Louisiana lose their Medicaid benefits when they enter in a facility considered a "lock up," so helping youth to get that coverage back when they return home has been a challenge.
- Multiple participants reflected on frustration with case management and following through with youth once they are no longer in their facility. Several mentioned that the first time youth are being seen for diagnosis are when they enter the facility.

> We're supposed to have an Americans with Disabilities Act (ADA) liaison specifically for screening, etc. We haven't had one.

> Medicaid won't pay for specialty or in-home [services] unless all state resources have been exhausted. So they'll apply for all state [services], then look out of state. Sometimes they are sent to state facilities like a residential treatment facility that isn't appropriate, but it is the only place. Or they sit in detention waiting for out-of-state.

Lessons Learned

Youth and young adults with IDD who have been in juvenile detention often sit at the intersections of race, ethnicity, language, socioeconomic, and educational disparities that can affect their ability to direct their health care transitions.

Families continue to play a role in youth accessing the health services they need, which demonstrates the importance of empowering and informing families to support youth and young adults. A supported decision-making process can be helpful to families as they help youth develop knowledge and skills to manage their own care. Supported decision making (SDM) “allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters” (ACLU, 2016). In some states, there are legal structures for supported decision making, but in other states, the process is less formal. Either way, supported decision making allows families to support youth in their health care decision making as they transition to adult health care.

Availability versus Access

Interventions like “case management, instructional materials, self-education programs, mentoring/navigation services, and electronic medical record transition” have been instrumental in supporting health care transition for youth and young adults with IDD (Okumura et al., 2021). These interventions are likely to be especially helpful for youth with IDD in juvenile detention centers.

While many services may be available to youth in detention, they may not know how to access the services or make the most of the investments to support youth health. In addition to making these services available, making youth and families aware of these services, and going further to actually help them use the services, arose as an important improvement on health care services for youth in detention.

> Kids who end up detained for a long time, with significant disabilities – their families generally cannot care for them because of their own disabilities or [because they have] exhausted all resources. ”

Recommendations

Based on the barriers and opportunities identified by youth who have been in juvenile detention centers and professionals who have worked in juvenile detention centers, there are several paths to support youth in transitioning to adult care.

Recommendations for Juvenile Justice Facilities

Help youth to reinstate their Medicaid benefits and/or SSI before they are released back into the community, when possible.

- Given that many youth who enter the juvenile justice system are the most vulnerable and come from low socioeconomic backgrounds, legislatures should reconsider state laws that cause youth to lose their Medicaid benefits when entering juvenile justice facilities. There should be a premium focus on ensuring a continuation of services and maintaining Medicaid benefits, which can help minimize treatment disruptions upon release.
- Allowing facilities to reenroll youth to Medicaid benefits while detained will also allow continuation of services and ensure that critical benefits and treatment plans continue upon release. This should be triggered as a part of a release plan prior to a youth's departure.

> While in detention, we pay for everything: medications, doctor's visits. But when they get home, trying to get that coverage back has been a challenge. To get the block removed from Medicaid, they need to show the dates they were there, but for most of them [the challenge] has been access to a computer to get online and reinstate the services.
>
> Even if we said, "This kid will be released tomorrow; can we get them reinstated?" they won't talk to them until they've been released. **But the best time to do it is when they're in our care**.

Recommendations

Recommendations for Juvenile Justice Facilities

Assign a long-term transitional coordinator (CYFD) and insurance care coordinators.

- Many juvenile justice facilities staff expressed frustration that parents did not seek guidance from long-term transitional coordinators. For some of these facilities, long-term transitional coordinators are assigned upon 30-day release dates. It may be beneficial to establish relationships with family members earlier, upon entry of the facility, as reuniting with the family may be a stressful and chaotic time for family members to consider HCT on top of other responsibilities.
- Other staff flagged concerns about having multiple staff members who hold different responsibilities, and at least one facility flagged they no longer have an ADA coordinator. These stresses highlight the complications experienced across the country with staff shortages. A serious effort needs to be made to recruit and retain quality facilities staff. Further, compliance checks need to be frequent to ensure all required staff roles are filled by a qualified staff member.
- What we don't know is the comfort level parents may have with having a transition coordinator. Some parents may feel discomfort or view the transition coordinator as an extension of juvenile justice facilities and may not want a coordinator extending contact with them. Some families may perceive this extended contact as too invasive, like child protective services (CPS). It may be important to establish that relationship for a longer period but also emphasize that this person is here to help and not get people in trouble.

> A lot of times it is environmental things causing [youth] to act out or get in trouble. But the sad part is, while the kid is getting treatment they need, the parent or caregiver is not having to do anything to prepare the kid to come back home. Then you're sending the kid back to the same environment. Having an advocate to help with that transition would be huge.

Recommendations

Recommendations for Juvenile Justice Facilities

Include health care transition as a treatment goal so the team can focus on connecting youth with resources and partners once they leave the detention facility.

- Several facilities staff stated that adult transition care was not a treatment goal, despite having 17-year-olds who are turning 18. All juvenile justice facilities should have policies that address how to transition youth from pediatric to adult care service providers effectively.
- Due to differences between the pediatric and adult care service systems, there should be specialized staff around health care transition who understand the transition process.

> The community in general doesn't have a good understanding of how adult care works or adult systems, specifically Developmental Disabilities (DD) waiver and how that exists and what it is. They need more education, and these systems need to be more readily available. We need more people to realize we have resource directories and maybe more people out in the field who are doing pop-up events. A lot of social groups for adults and youth with DD have parent groups that reach out. **Let them know there are transition supports**.

> NM state law says kids over 14 get complete **confidentiality** unless they are hurting themselves or others. For kids that we have noticed struggling or kids whose parents identify they need help but the kids decline, it's hardest. It is good and bad. We get to help kids lacking parental support when they are over fourteen, but kids desperately in need can still decline even with mental health counseling. We have had so many kids that decide they don't want to do counseling and they're allowed to make that decision.

Recommendations

Recommendations for 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.

- Many youth stated that their mothers assisted in their advocacy. This may speak to more parental involvement by mothers in the health care process or greater comfort in discussing health with a parent who is actively participating. Parent-child coaching or skill sessions could help youth build their confidence in talking to health care providers alongside a trusted figure. Building these advocacy skills is especially important for detained youth, as they lose a sense of agency and independence when entering the juvenile justice system.
- Health education courses should consider patient advocacy as a component of their curriculum.

Provide adequate time to share information with youth with IDD in a private setting.

- While youth and staff appeared to have ample time (20-30 minutes) for appointments, one area for improvement centers on confidentiality. Having juvenile justice facilities staff present in a medical appointment may influence a youth's transparency. This is particularly concerning if the youth wants to disclose any type of abuse. The youth might not feel comfortable sharing this with a staff member present.

Recommendations

Recommendations for Health Care Providers

Emphasize health care transition and different health care systems a child may be transitioning to as they become an adult.

- Several facilities staff expressed frustration that parents are unaware that their child will be entering a new system as they age out of the pediatric system. This confusion results in delays and gaps in health coverage, along with a disruption of continuity of care as the teen transitions to adult care. A greater emphasis needs to be placed on explaining this to parents long before a child's 18th birthday.
- Facilities staff should consider reminder systems like text messages or postcard notifications informing parents that their child will soon age out of the pediatric system. Similar notification systems have proven to be effective in the health care system to decrease missed appointments and to decrease failures to appear to court.

Find resources for health care providers to support health care transition for youth with IDD at movingtoadulthealthcare.org.

Recommendations

Recommendations for Youth with IDD and Their Families

Ask about options for services and care.

- Disability agencies and advocates can educate youth and families about ADA coordinators and other support persons. All juvenile justice facilities should have ADA coordinators, social workers, and transitional care staff who can help navigate these complex systems. Parents are encouraged to exercise their parental right to know which staff members hold respective roles so that they may be informed of all their options.

Ask about what you qualify for.

- Research has shown that strong teacher-parent relationships result in better student outcomes due to a partnership approach to a child's wellbeing. Similarly, establishing strong relationships with juvenile justice facility staff can help keep parents abreast of their child's progress and health in the facility. Maintaining those relationships and communication will also be helpful in ensuring that they are aware of all programs their child and family qualify for.

Ask to work with a care coordinator who can help connect you to services upon entry and, at minimum, during the release planning phase of disposition.

- Facilities staff create a release plan weeks, often months, prior to a child's release from a facility. Despite that lead time, some families are still caught off guard by the various bureaucratic processes, including health care transition, which may take a month to go into effect. Because of this lag time, parents should try to establish working relationships with care coordinators as early as possible to build familiarity with the system.

www

Find tools youth with IDD can use to guide their transition to adult health care at movingtoadulthealthcare.org.

Learn more about this topic

catch the replay

Pathways and Pitfalls

Helping Youth with IDD in the Juvenile Justice System Move to Adult Health Care

Funded by the WITH Foundation

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Center for Transition to Adult Health Care for Youth with Disabilities

- Watch the webinar based on this report in English or with Spanish interpretation.
- Visit www.familyvoices.org/healthcaretransition/youthindetention for a summary of the work on this initiative.
- Visit www.movingtoadulthealthcare.org, the website for the Center for Transition to Adult Health Care for youth with Disabilities, for information and resources about health care transition.
- Visit http://www.thearc.org/our-initiatives/criminal-justice to learn more about The Arc's National Center on Criminal Justice and Disability (NCCJD).

The intended outcome of this project is for youth and young adults with IDD who have been in juvenile detention centers to direct their own health care transition, with support from their families and the systems that serve them.

Health care transition is a key element to ensure that youth and young adults with IDD manage and maintain their physical and mental health into adulthood. We thank WITH Foundation for grant support for this project. Special thanks to the young adults and juvenile detention professionals who shared their experiences with us.

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FAMILY VOICES®

Family Voices transforms systems of care to better work for all children and youth, especially those with special health care needs and disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes. For more information, visit familyvoices.org/healthcaretransition.

The Arc.

National Center on Criminal Justice & Disability®

The Arc's National Center on Criminal Justice and Disability (NCCJD) serves as a bridge between the criminal justice and disability communities. NCCJD pursues and promotes safety, fairness, and justice for people with IDD, especially those with hidden disabilities and marginalized identities, as victims, witnesses, suspects, defendants, and incarcerated persons. For more information, visit thearc.org/our-initiatives/criminal-justice.

Center for
Transition to Adult Health Care
for Youth with Disabilities

The Center for Transition to Adult Health Care for Youth with Disabilities is a national health care transition resource center. The goal of the ACL-funded center is to empower youth and young adults with intellectual and developmental disabilities (ID/DD) ages 12-26 to direct their own transition from pediatric to adult care with no reduction in quality of care and no gaps in service. Learn more at movingtoadulthealthcare.org.