

Health Care Transition Barriers, Gaps, and Interventions for Youth and Young Adults with Intellectual and Developmental Disabilities: A Landscape Analysis

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This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award to Family Voices totaling \$2,425,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

INTRODUCTION

This landscape analysis examines gaps, disparities, and health care transition (HCT) interventions for youth and young adults (Y/YA) with intellectual and developmental disabilities (ID/DD), with a particular focus on underserved populations. The landscape analysis is a part of a larger five-year grant from the Administration on Community Living (ACL), described below. This analysis, which was completed in year one, was based on key informant interviews, literature reviews, and outreach to Family Voices and Title V programs in every state, Washington D.C., and the territories. Information is organized into three main sections: 1) literature review, highlighting barriers, disparities, and HCT interventions; 2) HCT resources for a future youth-driven website; and 3) product development. Findings will serve as a foundation for the rest of the grant efforts and understanding the HCT gaps and needs of this population.

Background

Clinical recommendations on HCT call for all Y/YA, ages 12-26, and families to receive guidance and support from their health care providers on the key elements of HCT.^a However, most youth, especially youth with ID/DD, do not receive recommended HCT support. According to the 2019/2020 National Survey of Children’s Health, only 20% receive HCT preparation from their health care providers.^b Past research has shown that youth with developmental, behavioral, and intellectual conditions were 25% less likely than their peers without these conditions to receive HCT preparation support.^c In addition, minoritized and low-income youth with autism spectrum disorder (ASD) were less likely to receive HCT services than their white and higher income peers.^d

A lack of HCT preparation guidance is associated with gaps in care, worsening health conditions, dissatisfaction with care, and increased rates of hospitalization.^{e,f} Many Y/YA with ID/DD and their families feel as if they have “fallen off a cliff” when it comes to their transition from pediatric to adult health care. Y/YA and families note that most of the work is left to them – building self-care skills, helping navigate health services, figuring out options for shared decision-making, finding a new adult doctor, and coordinating care plans.

ACL Project Aim

The ACL, in 2021, provided funding to establish a youth-driven National Health Care Transition Resource Center (NHCTRC) for Y/YA with ID/DD. The overarching goal of the NHCTRC is to empower Y/YA, ages 12-26, with ID/DD and their caregivers/families to manage HCTs without reduction in quality of care or gaps in services. The NHCTRC is guided by a Youth Steering Committee (YSC) to improve ways to support

^a White PH, Cooley WC, Boudreau AD, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5).

^b Bethell CD, Gombojav N, Sherwood A. Findings on Title V youth transition to adult care performance measures using the 2019-2020 NSCH. CAHMI, Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from HRSA/MCHB. Aug. 4, 2022.

^c Leeb RT, Danielson ML, Bitsko RH, et al. Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders — United States, 2016–2017. *MMWR*. 2020;69(34):1156-60.

^d Eilenberg JS, Paff M, Harrison AJ, Long KA. Disparities based on race, ethnicity, and socioeconomic status over the transition to adulthood among adolescents and young adults on the Autism Spectrum: A systematic review. *Curr Psychiatry Rep*. 2019;21(5):32.

^e Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *J Pediatr*. 2017;188:263-69.

^f Schmidt A, Ilango SM, McManus MA, et al. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing*. 2020;51:92-107.

Y/YA with ID/DD to direct their own HCT from pediatric to adult care. This will be achieved over the course of the five-year grant through:

- Creating a youth-guided NHCTRC and accompanying website and app
- Identifying gaps, disparities, and promising practices in HCT
- Fostering innovative HCT approaches, resources, and technical assistance on a national scale that are accessible and culturally and linguistically competent
- Accelerating the spread of promising HCT approaches that engage and empower Y/YA with ID/DD and their families/support networks to manage their HCT through a new State HCT Community of Practice (CoP) and a new HCT Project ECHO
- Building partnerships with key stakeholders to disseminate multimedia HCT tools and approaches

Leading this effort is Family Voices, with partners from Got Transition/The National Alliance to Advance Adolescent Health, SPAN, the University of Missouri-Kansas City (UMKC), and the Waisman Center.

LITERATURE REVIEW

The purpose of the literature review was to identify articles that address the HCT needs and barriers experienced by Y/YA with ID/DD and their families and health care providers, HCT and health care disparities, and examples of HCT interventions.

PubMed and Google Scholar were searched for peer-reviewed articles written in English from 2015-March 2022 using the following key words: health care transition, underserved, intellectual disability, developmental disability, gaps, disparities, barriers, challenges, empowerment, youth, young adults, interventions, minority, minoritized, equity, and LGBTQ. Article titles and abstracts were reviewed, and this process yielded 114 articles. After removing duplicates, each article was read for inclusion. Articles were excluded if they were not peer-reviewed and published in an academic journal, or if they were not related to HCT and ID/DD populations. This yielded a total of 68 remaining relevant articles, as shown in Appendix A.

The 68 articles were read and marked if they fell within the following categories. Note, articles could be marked for multiple categories.

1. Mention of barriers or challenges (36 articles)
2. Parent or caregiver perspectives (22 articles)
3. HCT models or interventions (18 articles)
4. Health care provider perspective or training (17 articles)
5. Y/YA perspectives (17 articles)
6. HCT evaluation study (15 articles)
7. Review (e.g., systematic review) (13 articles)
8. Practice recommendations, guidelines, or policy statements (11 articles)
9. Large data set analysis (8 articles)
10. Mention of disparities (8 articles)

HCT Barriers

Methods

A total of 60 articles were read and abstracted for barriers. These articles were those marked in categories 1, 2, 4, and 5 above (mention of barriers or challenges, parent or caregiver perspectives, health care provider perspectives or training, and Y/YA perspectives), and articles repeated within multiple categories were unduplicated.

To guide this analysis, the organization of barriers and challenges from the AAP/AAFP/ACP Clinical Report (CR) was used as a framework, though the CR drew on a larger body of literature related to youth with a range of conditions, not solely ID/DD.⁸

Following the CR framework, information was abstracted from each article on the following categories:

- a. Population that these barriers address (e.g., age and condition). A note was added if the article addressed barriers related to underserved populations.
- b. Youth, young adult, or family barriers: 1) fear of new system/hospital and adulthood, 2) inadequate planning, and 3) health care system difficulties.
- c. Clinician barriers: 1) communication/consultation gaps, 2) training limitations, 3) care delivery, care coordination, or staff support gaps, 4) lack of patient knowledge/engagement, and 5) lack of comfort with adult care.

If the article did not mention HCT barriers, it was omitted from the barriers analysis.

Findings

After abstraction, 36 articles were included in the barriers analysis. The HCT barriers experienced by Y/YA with ID/DD, families, and clinicians are listed in Table 1. The number in parentheses listed with each barrier indicates the number of times that barrier was reported in the literature.

The barriers identified in this analysis were similar for the Y/YA and family barriers in the CR, whereas this analysis did not identify certain clinician barriers included in the CR. Some examples are being worried that there was difficulty meeting the needs of Y/YA and families with potentially unrealistic expectations of time and attention, lack of confidence among pediatric providers with adult providers, lack of pediatric consultation availability, and lack of adherence by young adults.

⁸ White PH, Cooley WC, Boudreau AD, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5).

Table 1. Barriers Experienced by Youth, Young Adults, Families and Clinicians from Literature

Barriers experienced by youth, young adults, and families
<i>Fear of new adult system/hospital and adulthood</i>
<ul style="list-style-type: none"> • Fear of independence and changes that occur during adulthood^{4,14,15,31,45} (8) • Fear that adult clinicians will not listen to and value the patient/family's expertise^{9,14,20} (6) • Anxiety about leaving the pediatrician and pediatric system^{4,9,14,20} (4) • Feeling unprepared for the new adult health care system^{1,35} (2) • Parents worry about changes in guardianship^{4,14} (2)
<i>Inadequate HCT planning</i>
<ul style="list-style-type: none"> • Inadequate HCT preparation and lack of tools/education^{1,3,15,19,20,25,31,33,35,37,39,44-46,66-68} (31) • Poor and inconsistent communication about HCT^{3,5,19,20,25,38,39} (10) • Feeling judged, ignored, or perceived as inadequate by providers^{15,37,40,45,66,67} (7) • Lack of available support and infrastructure to help families transition^{14,46,47,64,66,67} (6) • Lack of time alone with health care provider^{15,25,38,67} (4)
<i>Health care system difficulties</i>
<ul style="list-style-type: none"> • Difficulty finding adult providers and support services/resources^{9,20,25,30,37,44,46,52,67,68} (16) • Lack of care coordination and communication between service providers and systems^{1,4,9,20,37,47} (9) • Issues with cultural responsiveness^{19,35,45,46} (6) • Issues accessing health care and insurance and discontinuity of care^{20,35,37,55,68} (5) • Rural health disparities^{9,35} (2) • Lack of accommodations for varying abilities³⁷ (1)
Barriers experienced by clinicians
<i>Communication/consultation gaps</i>
<ul style="list-style-type: none"> • Difficulty for patient/families to communicate with providers^{18,58} (2) • Lack of communication between pediatric and adult providers^{4,37} (2)
<i>Training limitations</i>
<ul style="list-style-type: none"> • Lack of provider training on specific conditions and how to address unique needs of Y/YA^{4,9,18,24,25,30,65} (9) • Lack of provider knowledge of HCT and their role in the process^{27,30,33,40,64,65} (9)
<i>Care delivery, care coordination, or staff support gaps</i>
<ul style="list-style-type: none"> • Lack of HCT guidelines and system supports^{3,18,24,25,34,57,64} (11) • Lack of available adult health care providers^{18,27,51,64,65} (6) • Lack of financial incentives for HCT preparation^{4,18,52,64} (4) • Lack of coordination between public service agencies and resources^{27,52,65} (4) • Appointment and logistics time constraints limit opportunities for HCT preparation^{18,25,64} (3)
<i>Lack of patient knowledge/engagement</i>
<ul style="list-style-type: none"> • Patient/family lack knowledge about their health, treatment, and the importance of HCT^{14,27,31,52} (6) • Patients lack self-care skills³¹ (3)
<i>Lack of comfort with adult care</i>
<ul style="list-style-type: none"> • Family/patient resistant to HCT¹⁸ (1)

See the Product Development section on page 10 for methods and findings of how these barriers were further reviewed and added to with the YSC.

HCT Disparities

Methods

A total of 8 articles were read and abstracted for disparities. These articles were those marked in category 10 above, "Mention of disparities." If the article did not describe disparities about health or HCT, it was omitted from the disparities analysis.

Findings

After abstraction, 6 articles among the 68 articles in the full literature review addressed disparities. Table 2 summarizes the disparities described in each article, including disparities in receipt of HCT services and disparities in health care access, cultural and disability sensitivity, and quality of care among transition-aged Y/YA with ID/DD and their families.

Table 2. HCT Disparities

Types of Disparities
<p>Receipt of HCT services</p> <ul style="list-style-type: none"> • Racial/ethnic minority youth with ASD less likely to receive HCT services than white peers¹⁹ • Among youth with ASD, Hispanic youth less likely to receive HCT services¹ • Among youth with ASD, those with multiple medical conditions less likely to receive HCT services¹ • Those with ASD had lower percentages of receipt of HCT services than other YSHCN³³ • Low-income youth with ASD less likely to receive HCT services compared to higher income peers¹⁹ • Youth with ADHD less likely than youth without ADHD to discuss transition planning²⁸ • Minority and low-income YSHCN less likely to receive HCT services compared to YSHCN overall¹ • Asians slightly less likely than whites to discuss transition planning²⁸
<p>Access to care</p> <ul style="list-style-type: none"> • Racial/ethnic minority children with ASD are diagnosed 1.5 years later than white peers¹⁹ • Children with ASD from lower income families were less likely to be diagnosed timely with ASD and have decreased access to health services compared to higher income peers¹⁹ • Racial/ethnic minority children with ASD have decreased access to ASD services compared to white peers¹⁹ • Latino children and adolescents with ASD and other ID/DD had worse rates of health care access and utilization compared to white peers²⁸ • Latino children and adolescents with ASD receive fewer specialty health care services compared to white peers²⁸ • Racial/ethnic minority youth reported more unmet healthcare needs than white peers¹⁹ • Children with developmental disabilities experienced the greatest disparities in unmet health care needs, compared to a peer group without developmental disabilities of the same age⁴⁹
<p>Cultural sensitivity</p> <ul style="list-style-type: none"> • For black and Latino patients, health care providers did not show as much sensitivity to family values, compared to white peers²⁸ • Asian and white respondents more likely to report their doctor showed sensitivity to their customs and values compared to Hispanic and black youth²⁸
<p>Disability sensitivity</p> <ul style="list-style-type: none"> • For youth with ASD, new doctor's offices may create obstacles that are not experienced by other YSHCN due to communication challenges and sensory responses to environmental stimuli³³ • Patients with intellectual disability, history of aggressive behavior, or seizures were more likely to need adjustment to the standard patient flow⁵³
<p>Quality of care</p> <ul style="list-style-type: none"> • Hispanic youth and black youth less likely to report their provider spent enough time with them compared to Asian and white respondents²⁸ • Latino children and adolescents with ASD and other ID/DD had worse rates of health care quality compared to white peers²⁸

HCT Interventions

Methods

A total of 30 articles were read and abstracted for the HCT interventions analysis. These articles were those marked under HCT evaluation study and HCT models or interventions (categories 6 and 3 on page 2) and included a mix of professional statements and intervention evaluation studies. Overlapping articles between categories were unduplicated.

To guide this intervention analysis, Got Transition’s Six Core Elements of HCT was used as a framework.^h Information was abstracted from each article and marked according to the following categories:

- a. Population that these barriers address (e.g., age and condition)
- b. HCT policy
- c. HCT tracking
- d. HCT readiness/self-care skills assessment
- e. Plan of care/medical summary
- f. Education about self-care skills advocacy
- g. Prepare transfer package
- h. Welcome/orientation to adult practice
- i. Assistance finding/scheduling appointments with adult health care providers
- j. Communication/consultation between pediatric and adult health care providers
- k. Appointment reminders
- l. Coordinator
- m. Transition clinic/specific transition appointment
- n. Other

If no information on intervention activities were mentioned in the article, it was omitted from the interventions analysis. Abstracted information from the “other” category was reviewed and common interventions were grouped together to form additional categories of intervention types. Added categories include:

- a. Y/YA and family education/discussion and assistance with resources
- b. Communication/accommodations for Y/YA and families
- c. Provider education
- d. Guardianship/supported decision-making
- e. Multi-agency coordination/partnership
- f. Y/YA and family feedback or follow-up
- g. Mentorship
- h. Electronic medical record (EMR)-based transition tools

Abstracted information about the intervention activities were then organized by the Six Core Elements and by clinical processes. Examples of accommodations were also abstracted and sorted by 1) physical accommodations, 2) communication and cultural accommodations, and 3) attitudinal accommodations.ⁱ

Findings

After abstraction, 27 articles were included in the intervention analysis. Tables 3a, 3b, and 3c show the different conditions studied, types of HCT intervention activities, and examples of accommodations for Y/YA with ID/DD.

^h White P, Schmidt A, Ilango S, et al. *Six Core Elements of Health Care Transition™ 3.0*. Washington, DC: Got Transition, The National Alliance to Advance Adolescent Health, July 2020.

ⁱ Disability and Health Inclusion Strategies. Centers for Disease Control and Prevention. Accessed on 8/22/22 at <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-strategies.html>.

Table 3a. HCT Interventions – Conditions Studied

Conditions studied	Article count
Intellectual and/or developmental disability	12 articles ^{2,12,16-18,21,32,39,51,56,57,59}
Autism Spectrum Disorder	9 articles ^{12,18,24,25,30,34,35,39,56}
Cerebral palsy	5 articles ^{12,18,21,39,56}
Mental health conditions/co-morbidity	4 articles ^{16,17,26,39}
Epilepsy	2 articles ^{11,12}
Duchenne Muscular Dystrophy	2 articles ^{12,58}
Medical complexity	2 articles ^{51,57}
Neurological conditions/disease	2 articles ^{12,64}
Spina bifida	2 articles ^{21,47}
22q11 Deletion Syndrome	1 article ¹⁸
Congenital disorder	1 article ⁵⁶
Down syndrome	1 article ³⁹
Genetic disorder	1 article ⁵⁶
Learning disabilities and/or ADHD	1 article ³⁹
Metabolic disorder	1 article ⁵⁶
Prematurity, prenatal or perinatal insults	1 article ³⁹
Tuberous Sclerosis Complex	1 article ⁴⁸
Youth with special health care needs (conditions not specified)	1 article ⁴³
Children with disabilities (all-inclusive)*	1 article ²⁹

Note: Some articles looked at multiple conditions. They are counted multiple times.

**NAS report that defines disability as “an environmentally contextualized health-related limitation in a child’s existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society”*

Table 3b. HCT Interventions – HCT Approach and Clinic Processes for Y/YA with ID/DD

Intervention type	Article count
Transition and care policy/guide (Core Element 1)	
Transition policy	8 articles ^{12,17,18,24,26,39,57,64}
Welcome/orientation to adult practice	1 article ³⁹
Tracking and monitoring (Core Element 2)	
HCT tracking	6 articles ^{25,26,39,43,57,64}
Transition readiness (Core Element 3)	
Education about self-care skills and advocacy	17 articles ^{2,11,12,16,18,24-26,29,34,35,39,47,51,57,58,59}
Readiness/self-care assessment	14 articles ^{2,11,12,16,18,21,25,26,39,43,47,58,59,64}
Transition planning (Core Element 4)	
Plan of care/medical summary	14 articles ^{2,11,12,17,18,21,25,26,34,39,43,47,59,64}
Assistance finding/scheduling visit with adult health care provider	9 articles ^{11,12,25,26,34,39,51,57,58}
Y/YA and family education/discussion and assistance with resources	6 articles ^{12,18,25,34,56,59}
Guardianship/supported decision-making	4 articles ^{12,25,29,39}
Mentorship	1 article ²¹
Transfer of care (Core Element 5)	
Communication/consultation between health care providers	13 articles ^{2,11,12,16,17,25,26,29,39,48,51,58,64}
Prepare transfer package	9 articles ^{2,12,17,18,26,39,48,57,64}
Appointment reminders	1 article ⁴³
Transfer completion (Core Element 6)	
Y/YA and family feedback or follow-up	2 articles ^{25,64}
Clinic processes	
Coordinator	10 articles ^{16,17,18,29,32,34,39,51,56,58}
Transition clinic/specific appointment	7 articles ^{11,16,18,25,32,34,48}
Communication/accommodations for Y/YA and families	6 articles ^{12,24,29,35,43,58}
Provider education	5 articles ^{11,12,16,30,34}
Multi-agency coordination/partnership	3 articles ^{12,16,17}
EMR-based transition tools (e.g., prompts to document HCT planning)	1 article ⁵⁷

Table 3c. HCT Interventions – Examples of Accommodations

Example accommodations
<i>Physical accommodations (e.g., wheelchair access)</i>
<ul style="list-style-type: none"> • Create accessible space⁴³ • Offer patients alternative to overstimulating waiting room²⁴
<i>Communication and cultural accommodations (e.g., plain language, translation)</i>
<ul style="list-style-type: none"> • Communication such as voice output devices, interpreters, Picture Exchange Communication System⁴³ • Allow patients to communicate with preferred method such as writing, use specific and precise language²⁴ • ASD-specific curriculum into educational programming for family nurse practitioner students³⁰ • Proficiency in the lexicon of ID/DD (impairment, disability, and handicap)⁵⁹ • Cultural adaptation of a “Transitioning Together” intervention³⁵ • Interventions need to be thoroughly attuned to the cultural and linguistic backgrounds of their recipients³⁹ • Providers should proactively engage the family, openly discussing differences in culture and asking about particular anxieties they might have⁵⁶
<i>Attitudinal accommodations (e.g., emphasize abilities, not limitations, implicit bias)</i>
<ul style="list-style-type: none"> • Parents/peer mentors need to recognize the capacity of the youth to complete the worksheets themselves²¹ • Goals should be designed to promote increased patient autonomy and responsibility for management of their own care⁴⁷

HCT RESOURCES FOR WEBSITE

Resource Identification

Methods

Key informant interviews and online surveys were conducted to identify existing, online HCT resources developed for Y/YA with ID/DD, their families, and/or health care providers within the following topic areas, which can be used for the future NHCTRC website:

- a. General/introduction to HCT
- b. Legal rights and responsibilities for health care at age 18
- c. Transition readiness/self-care skills assessment
- d. Plan of care/medical summary that incorporates HCT
- e. HCT self-advocacy skill building
- f. Communicating with providers about HCT
- g. Accessing personal medical and behavioral health information
- h. Steps to find an adult health care provider
- i. Differences between pediatric and adult health care
- j. Information about staying insured
- k. Leading day-to-day health routines
- l. Other HCT resources
- m. Resources for health care clinicians
- n. Resources for direct service providers/community outreach workers/advocates

Key informants were also asked if they could provide links to any HCT initiatives for underserved Y/YA with ID/DD, including racial/ethnic minorities, those who identify as LGBTQ, those involved in criminal justice, those in foster care, and those with mental/behavioral health co-morbidities.

An online survey that replicated the key informant interview questions was distributed to all state Title V agencies and state councils on developmental disabilities and selected national organizations.

Findings

A total of 25 key informant interviews were conducted, including with Family Voices, SPAN, UMKC, the Waisman Center, in addition to national disability organizations, selected ACL-funded centers, and selected University Centers of Excellence on Developmental Disabilities (UCEDDs). The online survey was completed by 33 respondents, mostly from state Title V agencies. See Appendix B for the complete list of organizations and states who provided input.

In total, 373 links to resources/tools/webpages were provided via interviews and surveys. Although some organizations mentioned past and ongoing efforts for underserved populations, they did not have hyperlinks to summaries or reports and thus their efforts were not included in our findings.

Preliminary Resource Curation for Website

Methods

Resources were reviewed and omitted if they were created before 2013, were not specific to HCT (e.g., resources focused on education and employment transitions without incorporating health), were too state-specific and not generalizable, links were broken, or were duplicates.

Remaining resources were categorized in several ways:

- a. as resources with ID/DD specific HCT information (i.e., in plain language or developed by a disability organization) vs. resources with general HCT information.
- b. as resources for Y/YA vs. resources for parents/caregivers; if resources addressed both groups or were ambiguous, they were included in both categories.
- c. by the topic areas listed above in the Resource Identification methods. If resources were relevant to multiple topics, they were duplicated.

Findings

After curation, 159 of the 373 resources/tools/webpages met the inclusion criteria. If resources were relevant to multiple resource categories, they were duplicated across categories. With this duplication, there is a total of 242 resources. The number of unique resources varied greatly by category, as shown in Table 4.

Table 4. Distribution of HCT Resources

Category of Resources	Unique Resources
General/introduction to HCT	51
Legal rights and responsibilities for health care at age 18	32
HCT self-advocacy skill building	29
Resources for clinicians	19
Transition readiness/self-care skill assessment	14
Plan of care/medical summary that incorporates HCT	10
Communicating with providers about HCT	10
Steps to find adult health care provider	8
Information about staying insured	7
Leading day-to-day health routines	7
Resources for direct service providers	4
Differences between pediatric and adult health care	3
Accessing personal medical and behavioral health information	1

These resources will be further reviewed for use in the NHCTRC website for Y/YA, families, and health care providers to access. In addition, future efforts with this grant will address the gaps in resources identified through this process, including the identification of HCT interventions for underserved Y/YA with ID/DD.

PRODUCT DEVELOPMENT

HCT Barriers with Youth Steering Committee (YSC)

The list of barriers faced by Y/YA identified in the literature was re-written in plain language and formatted following the Green Mountain Self-Advocates Plain Language Checklist.^j

This list of HCT barriers was then shared with the YSC. Over an interactive Zoom meeting between Got Transition and the YSC, each barrier was reviewed and edited. Several barriers were added to the list and some existing barriers were edited based on their feedback. For example, the YSC added more specific barriers about why they do not feel ready to leave their pediatrician, why it is hard to find an adult doctor, and how they feel their doctor should prepare them for the transition. See Appendix C for the final compiled list of Y/YA barriers.

HCT Among Youth with ID/DD: 2022 Data Profile

ID/DD prevalence and HCT performance data from the 2019-2020 National Survey of Children’s Health were analyzed by the Data Resource Center for Child and Adolescent Health.^k Prevalence data for youth ages 12-17 were drawn from a list of 10 ID/DD conditions, including ADD/ADHD, ASD, cerebral palsy, Down syndrome, epilepsy or seizure disorder, intellectual disability, learning disability, speech or language disorder, and Tourette syndrome. The ID/DD prevalence estimate in the profile does not include ADD/ADHD, although the HCT performance estimates include all 10 conditions. The HCT performance estimate is based on meeting the following three criteria: 1) doctor spoke with child

^j Green Mountain Self-Advocates’ Plain Language Checklist. Accessed on 8/22/22 at <https://selfadvocacyinfo.org/wp-content/uploads/2019/08/Plain-Language-Checklist.pdf>

^k Bethell, CD, Gombojav, N, Sherwood, A. Findings on Title V youth transition to adult care performance measures using the 2019-2020 NSCH. CAHMI, Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, HRSA, MCHB. August 4, 2022.

privately without an adult in the room during the last visit, 2) doctor actively worked with youth to gain skills and understand changes in health care that happen at age 18, and 3) doctor discussed shift to providers who treat adults. No comparable data are available for those ages 18-25 on HCT preparation from national data sources.

An infographic profile was created to highlight this information. See Appendix D for the profile. This profile will be updated annually.

CONCLUSIONS

This landscape analysis draws on a variety of information sources to report on HCT barriers, gaps, and HCT interventions for Y/YA with ID/DD and their families. It can be referred to throughout the remainder of this ACL-funded effort to inform future activities for this grant including website design, products/deliverables, and services. The following key findings will guide this work:

- Most Y/YA with ID/DD and their families have not received preparation from their health care providers about the transition from pediatric to adult care (Appendix D).
- Of the articles studied, the main HCT barriers reported by Y/YA with ID/DD and their families relate to inadequate HCT planning such as lack of preparation and inadequate tools/resources (Table 1). The main HCT barriers reported by clinicians caring for Y/YA with ID/DD were barriers related to care delivery, care coordination, or staff support gaps such as lack of HCT guidelines and system supports (Table 1).
- The YSC perspective strengthened the list of HCT barriers as it is now inclusive of their voices and experiences (Appendix B).
- Few articles studied disparities in relation to HCT and Y/YA with ID/DD. Of those that did, disparities in receipt of HCT preparation/support, access to care, cultural sensitivity, disability sensitivity, and quality of care among Y/YA with ID/DD were found by race, ethnicity, income, and condition (Table 2). For example, racial/ethnic minority youth with ASD were less likely to receive HCT services compared to their white peers.
- Of the studies found that discuss interventions and/or recommended HCT services for Y/YA with ID/DD, many focused on particular diagnoses that would be considered ID/DD conditions such as ASD, cerebral palsy, and epilepsy (Table 3a). Using the Six Core Elements framework, the most common HCT intervention activities identified were related to Core Element 3 (Transition Readiness) and Core Element 4 (Transition Planning) (Table 3b). A common clinic process implemented or recommended was care coordination (Table 3b). Examples of suggested accommodations for Y/YA with ID/DD include cultural adaptations of HCT tools, creation of accessible spaces, and promotion of patient self-management (Table 3c).
- A range of HCT resources are available that can be part of the future NHCTRC website, particularly for Y/YA and families related to general/introductory information about HCT, legal rights and responsibilities, and HCT self-advocacy skill-building (Table 4). A handful of HCT resources for clinicians were also found. The most common gaps in available HCT resources for this population were identified, including resources on accessing personal medical and behavioral health information, differences between pediatric and adult care, leading day-to-day health routines, and information about staying insured.

Several limitations of this landscape analysis are important to consider. First, conclusions should be taken cautiously as this field of work on HCT for this population is relatively new. In addition, while this was not a systematic review, findings from the literature were concluded based on a thorough and iterative examination of peer-reviewed articles. This process, including topics of interest, was developed and added to. In regard to resources identified for the future website, only hyperlinks that were submitted/shared by organizations or key informants via interviews or online surveys were reviewed. Due to the limited timeframe, websites of nonrespondents were not reviewed for potential resources. Finally, it is important to note the wide variety of definitions and varying conditions used to define ID/DD and, where possible in this report, specific conditions in reference are listed out.

Regarding next steps, the Core Project Team, the YSC, the National CoP, and the ACL Project Officer will develop a plan to further curate the HCT resources for the future website; program strategies addressing barriers, gaps, and disparities in HCT that will be part of the future HCT kits and State CoP efforts; and recommendations for product development and dissemination strategies. Particular attention will be given to the needs of Y/YA from underserved populations.

APPENDIX A. LITERATURE REVIEW REFERENCES

Articles Reviewed for Barriers, Disparities, and HCT Interventions (68 articles)	
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APPENDIX B. KEY ORGANIZATIONS INTERVIEWED AND SURVEYED

Key Informant Interviewees

1. Family Voices
2. SPAN Parent Advocacy Network
3. University of Missouri-Kansas City
4. Waisman Center
5. American Academy of Developmental Medicine & Dentistry (AADMD)
6. American Association on Intellectual and Developmental Disabilities (AAIDD)
7. Association of University Centers on Disabilities (AUCD)
8. Autism Speaks
9. Autistic Self Advocacy Network
10. Baylor College of Medicine
11. Center for Dignity in Healthcare for People with Disabilities (University of Cincinnati, Cincinnati Children's Hospital Medical Center)
12. Center on Youth Voice, Youth Choice/Institute for Community Inclusion (University of Massachusetts)
13. Easterseals
14. Georgetown
15. Hands and Voices
16. Indiana University
17. Kennedy Krieger Institute (Maryland Center for Developmental Disabilities)
18. National Association for State Directors of Developmental Disability Services
19. National Association of Councils on Developmental Disabilities
20. National Black Disability Coalition
21. PACER Center
22. Self Advocacy Resource and Technical Assistance Center (SARTAC), operated by Self-Advocates Becoming Empowered (SABE)
23. Special Olympics
24. University of Minnesota Institute for Community Integration
25. WITH Foundation

Online Survey Completers

Organizations

1. ASK Resource Center/Iowa
2. Baylor Transition Medicine Clinic/Texas
3. Institute for Disability Research, Policy & Practice
4. MAHEC Family Health Center at Biltmore, North Carolina
5. National Down Syndrome Congress
6. National Training Center for Mental Health and Developmental Disabilities/Utah State University
7. Parent to Parent USA
8. Self Advocacy Resource and Technical Assistance Center (SARTAC)
9. Self Advocates Becoming Empowered (SABE)
10. Sooner SUCCESS/Oklahoma
11. Statesville North Carolina
12. The RAISE Center

13. Vermont Family Network
14. Virgin Islands Developmental Disabilities Council, Inc.

State Title V Agencies

1. Alaska
2. Arizona
3. Arkansas
4. Connecticut
5. Georgia
6. Hawaii
7. Idaho
8. Louisiana
9. Minnesota
10. Nebraska
11. New Mexico
12. North Carolina
13. North Dakota
14. Pennsylvania
15. South Carolina
16. Tennessee
17. Utah
18. Washington
19. West Virginia

APPENDIX C. HCT BARRIERS LIST WITH YSC INPUT

Barriers to Health Care Transition

Health care transition is the process of getting ready for health care as an adult. Part of health care transition is learning to take care of your own health. Some parts of health care transition can be tough. Below are some of the feelings young people have about health care transition, gathered from the Youth Steering Committee and academic journal articles.

1. I am nervous about being an adult.
2. My doctor only talks to my family and not to me.
 - Doctors are not educated about disability.
 - I am not included in discussions or planning with my doctor.
 - Doctors do not have the patience to listen to me.
 - There are no text communication options.
 - I am not respected as a person by my doctor. They only see my disability.
3. I do not have enough information about self-advocacy.
 - I am unprepared to advocate for my health.
 - I did not have information about patient advocates.
4. I have not had time alone with my doctor in order to self-advocate without my parent or caregiver.

5. I have not seen my pediatric doctor in a long time because I am too old.
6. My doctor's office is far away or hard to get to.
 - It can be expensive and inconvenient to transport to my doctor's office.
 - I do not know how to access public transportation to get to my doctor's office.
 - It is hard to make plans to get to my doctor's office because it takes a lot of executive functioning skills.
7. I am not ready to leave my pediatrician.
 - I feel my needs won't be met in adult care.
 - I am not ready for these changes. Change is disruptive.
 - I worry that my new adult doctor will not listen to me.
8. It is hard to find an adult doctor....
 - ...because I live in a rural area.
 - ...that is the right fit for me.
 - ...because there is not a good way to navigate lists of doctors.
 - ...because the information is not already organized in a way I can understand.
 - ...because I don't know where to look.
9. The transition process is hard when you have lots of doctors. There are so many portals to keep track of.

10. The transition process is hard because it is a lot of added work to my life and takes lots of extra time and energy.
11. No one explained how my health care would change when I become an adult.
 - Doctors should be trained and responsible for easing health care transition so they can explain these changes when I become an adult.
 - Doctors should prepare us for transition beforehand, so we are not pushed into it.
 - Doctors should prepare us before the visit, so we have time to look up information and ask questions during the visit.
 - Doctors should tell us their policy about the age we need to leave their practice.
12. There is not a clear age for when youth ends and when young adulthood starts.
13. Doctors should not assume parents or caregivers are responsible for explaining transition.
14. The young person should be heard correctly, in a nice and kind way.
15. I do not know how to ask or who to ask questions about health care transition to.
16. I do not feel comfortable asking a doctor about health care transition.

17. My doctor does not know or is not accepting of my cultural, identity, or language preferences.
 - The doctor may not be able to provide an ASL interpreter.
 - I feel like my doctor may not be culturally competent.
18. My doctor's office does not know how to handle my disabilities.
 - There are accessibility issues.
 - Doctors are not educated about disability.
 - Doctors need to support a patient according to the patient's disability, symptoms, and needs.
 - Doctors need to understand and accept that patients come from different situations and process information differently.
 - Doctors should not assume that patients know medical or technical terms and it is uncomfortable to ask them to explain.
 - Doctors who use cursive make it difficult to read medical summaries.
19. I do not know how to keep my insurance.
 - I cannot afford my own insurance or co-pay and have trouble budgeting for this.
 - I don't have a way to make insurance payments.
20. My adult doctor did not have my new health information.
 - We do not always know how to get our health information to the new adult doctor.

- I don't know how to contact my pediatrician to get this information. It can be especially hard if they don't have text communication options.
21. There can be challenges with telehealth such as difficulties accessing internet or a smartphone or time limits with virtual appointments.

HEALTH CARE TRANSITION among youth with intellectual and/or developmental disabilities

What is health care transition (HCT)?



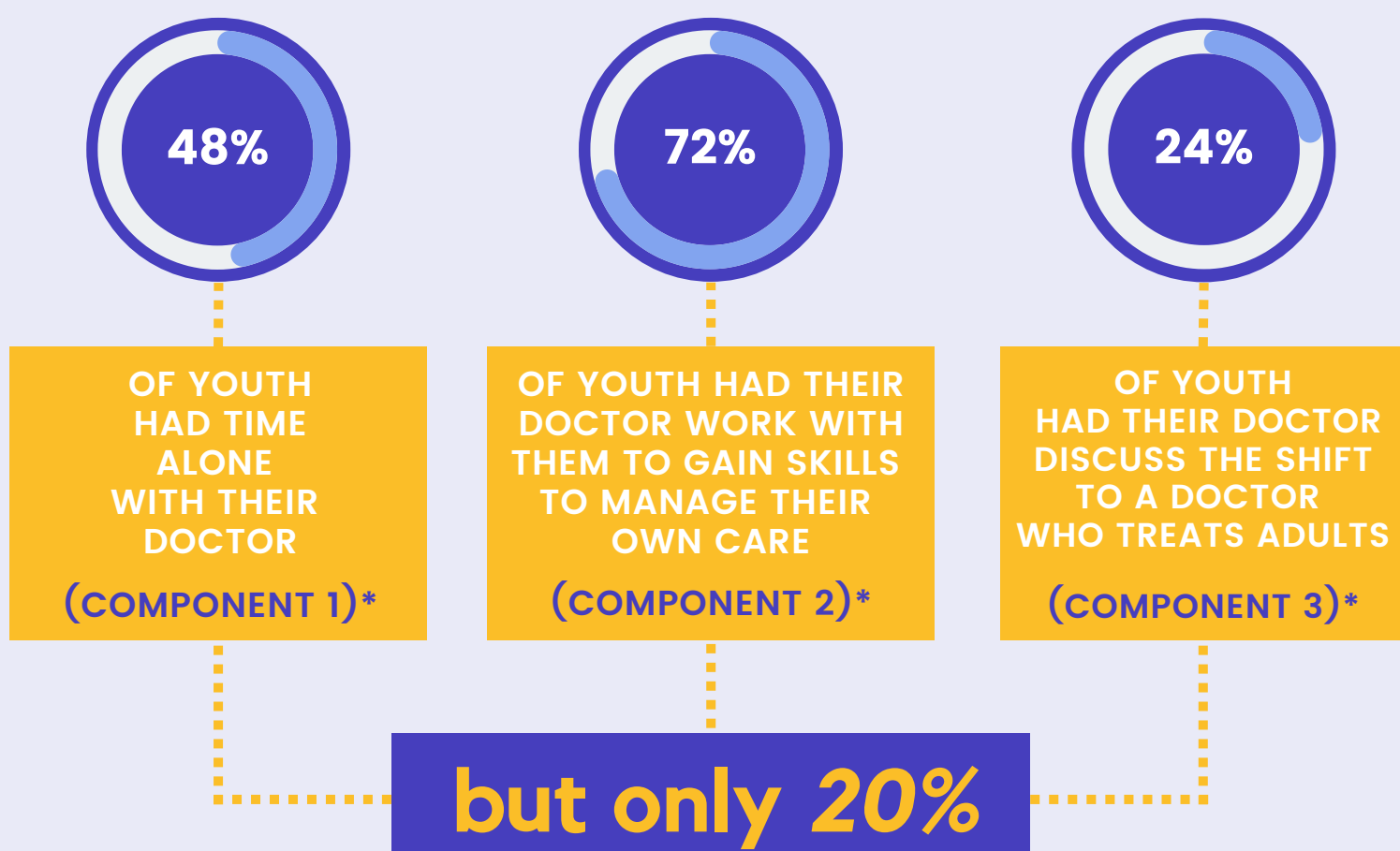
- HCT is the process of moving from a pediatric to an adult model of health care
- The goal of HCT is to learn skills to manage your own health and health services, with support

What is the prevalence of intellectual and/or developmental disability (ID/DD)?

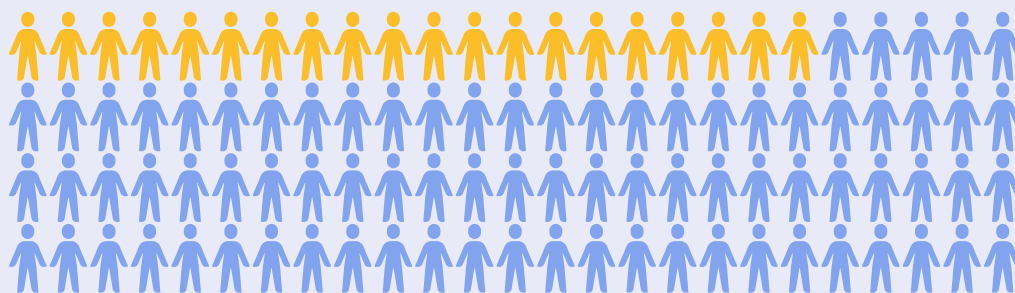
7% of youth, ages 12-17, have ID/DD¹

Among those ages 3-17 there has been almost 10% increase in the prevalence of ID/DD between 2009 and 2017²

How many youth, ages 12-17, with ID/DD receive HCT preparation guidance?



of youth received all 3 components of HCT³ preparation guidance from their doctor



*This data is from the 2019-2020 National Survey of Children's Health (NSCH). The respondent to this questionnaire is a parent or guardian who is living in the home and has knowledge of the sampled child.

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 -ID/DD is defined to include any current experience of autism or autism spectrum disorder (ASD), cerebral palsy, developmental delay, Down syndrome, epilepsy or seizure disorder, intellectual disability, learning disability, speech or language disorder, and Tourette syndrome.

2. Zablotsky B, et al. Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. Pediatrics. 2019;144(4).
 -ID/DD is defined to include attention-deficit/hyperactivity disorder (ADHD), ASD, blindness, cerebral palsy, moderate to profound hearing loss, learning disability, intellectual disability, seizures, stuttering or stammering, and other developmental delays.

3. Bethell CD, Gombojav N, Sherwood A. Findings on Title V youth transition to adult care performance measures using the 2019-2020 NSCH. CAHMI, Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from HRSA/MCHB, Aug. 4, 2022.
 -ID/DD is defined to include any current experience of attention deficit disorder or ADHD, autism or ASD, cerebral palsy, developmental delay, Down syndrome, epilepsy or seizure disorder, intellectual disability, learning disability, speech or language disorder, and Tourette syndrome.

Acknowledgment

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$2,425,000 with 100% funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

National Health Care Transition Resource Center

FOR YOUTH AND YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

