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## Improved health care transition for young adults with developmental disabilities referred from designated transition clinics

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### ABSTRACT

**Purpose:** Young adults with intellectual/developmental disabilities (YAIDD) are a vulnerable population during HCT due to their complex care coordination and adaptive needs, yet factors associated with transition preparedness are not well defined. We aimed to determine factors associated with health care transition (HCT) preparation satisfaction for YAIDD establishing care with an adult medical home.

**Design and methods:** 408 YAIDD or their families completed the HCT Feedback Survey 2.0 upon establishing adult care. Logistic regression models were used to determine associations between a composite of six HCT Feedback Survey questions that most correlated with the 2019 National Survey of Children's Health transition questions.

**Results:** YAIDD who had HCT preparation visits with a designated HCT clinic were 9 times more likely to have met all six composite HCT criteria after controlling for the number of technologies required and race/ethnicity (adj OR 9.04, 95% CI: 4.35, 18.76) compared to those referred from the community. Compared to patients who were referred from the community, the odds of feeling very prepared versus somewhat or not prepared were 3.7 times higher (adj OR 3.73, 95% CI: 1.90, 7.32) among patients referred from a designated HCT program.

**Conclusions:** YAIDD who participated in a structured HCT program prior to transfer to adult care experienced higher transition preparation satisfaction.

**Practical implications:** A structured HCT clinic model to prepare adolescents with DD for transition to adult care may improve HCT preparation satisfaction for this population.

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### Introduction

Transition from pediatric to adult care is defined as the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems (American Academy of Pediatrics et al., 2002). Health care transition (HCT) initiatives aim to maximize lifelong functioning and potential for adolescents and young adults with chronic conditions by providing high quality healthcare that is uninterrupted, coordinated, and developmentally and psychosocially appropriate (American Academy of Pediatrics et al., 2002; Rosen et al., 2003). Youth with special healthcare needs (YSCHN) are defined as those who have a chronic physical, developmental, behavioral, or emotional condition and extra health services and supports (McPherson et al., 2018). The National Survey of Children's Health (NSCH) 2018–2019 reported that 22.9% of YSCHN met the National

Performance Measure for receiving HCT services (i.e. meeting all three of the following HCT components: the doctor spoke privately with the adolescent, discussed transition, and worked with the adolescent to gain skills and understand health care changes) (Child and Adolescent Health Measurement Initiative, 2020). Without appropriate HCT supports, YSCHN are at risk for medical complications, decreased treatment adherence, discontinuity of care, and dissatisfaction, which may contribute to higher acute care use (Okumura et al., 2012; Shepard et al., 2018).

A subset of YSCHN who are particularly vulnerable during HCT are those with intellectual and/or developmental disability (IDD), defined as chronic intellectual and/or physical impairment manifesting during childhood that results in substantial self-care, language, learning, mobility, and independent living limitations (Cheak-Zamora & Thullen, 2017; Rudy et al., 2006). Young adults with IDD (YAIDD) often require additional HCT planning, navigation, and care coordination supports due to their on-going medical, adaptive, and behavioral care needs (Beal et al., 2016). Unfortunately, due to individual, family, health care

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system, and health policy barriers, YAIDD often have unmet HCT needs (Cheak-Zamora & Thullen, 2017; Heron et al., 2020; Lotstein et al., 2005; White et al., 2018).

While structured HCT approaches have yielded positive outcomes for YSCHN in general (Lotstein et al., 2008; Schmidt et al., 2020), there is limited research specifically evaluating HCT preparation for YAIDD. This retrospective study aimed to determine the association between the pediatric referral source and HCT preparation outcomes for YAIDD establishing primary care with an academic center-based medical home for adults with IDD. Findings may inform further research to improve HCT services for this population.

## Methods

### Study design and protocol

After receiving approval from the Baylor College of Medicine Institutional Review Board, investigators reviewed electronic health records of patients who established care between November 1, 2015 and December 31, 2019 at a medical home primary care clinic for adults with IDD. The clinic is affiliated with both adult and pediatric academic healthcare systems in a tertiary care medical center, and the clinic care team includes physicians, nurses, and social workers with expertise in caring for adults with IDD (Berens & Peacock, 2015). Patients were included if they had a diagnosis of autism spectrum disorder, cerebral palsy, Down syndrome, genetic syndromes, spina bifida, or other IDD-related diagnoses; were transferring from a pediatric clinic; and completed a Got Transition.org® Sample Health Care Transition Feedback Survey 2.0 at their initial visit (Got Transition, 2014). The authors reviewed clinic notes and electronic health care record problem list to determine the criteria for inclusion. The clinicians standardly use the problem list to document the patients' medical summary including the primary diagnosis and the diagnosis of intellectual disability. The social work team standardly reviews the referral source for each patient and documents this information on their intake note for all patients. Individuals were excluded if survey results were unavailable or if they were transferring from another adult clinic. The cohort size was determined by convenience sample. Patients or their families completed paper surveys in a private clinic room with social work staff available to read the questions or fill out the responses as needed. Patients and families could decide who completed the survey form, but patients were encouraged to complete it if they were able. Surveys were available in English and Spanish. Survey responses, demographic, and clinical data were entered into a standardized form in the institution's RedCap database (Harris et al., 2009, 2019). All RedCap entries were verified by an additional author to ensure accuracy.

### Measurements

The HCT Feedback Survey 2.0 is a 17-item questionnaire for patients or parent/caregivers that includes Likert scale multiple choice and yes/no questions assessing the patient/family's HCT preparation experience (Got Transition, 2014). Demographic and Clinical variables measured reflect the HCT theoretical model described by the HCT Research Consortium in 2014 (Betz et al., 2014). Demographic variables collected were age at the time of the last visit at the referring pediatric clinic before transfer to adult care and age at the first adult visit, race/ethnicity, primary household language (English or non-English), primary insurance (private or public, i.e. Medicare or Medicaid), and active home and community-based waiver status. Clinical variables included diagnosis of intellectual disability (as documented in the health record history), primary developmental disability diagnosis, and medical technologies used (ventricular shunt, vagal nerve stimulator, baclofen pump, tracheostomy tube, ventilator, feeding tube, and wheelchair). The included medical technologies represented those most used by the clinic patient population on a continual basis. These technologies

indicate additional complexity as they require extra navigation supports for supplies/equipment and often additional subspecialists for care. The pediatric care referral source was categorized into three groups: (1) *community referral*: primary care providers not affiliated with the pediatric hospital system, advocacy groups, schools, insurance/waiver care coordinators, friends or family, transition meeting venues, or website; (2) *affiliated pediatric hospital system referral*: primary or subspecialty physicians, nurse coordinators, or social workers within the pediatric hospital system; or (3) *a designated HCT clinic referral*: a specialized HCT clinic in the pediatric hospital's spina bifida clinic or complex care clinic wherein the patient and family received structured HCT preparation visits. In the spina bifida transition clinic, adolescents aged 14 and above were referred from the spina bifida multidisciplinary clinic and had visits with a physician, nurse educator/care coordinator, and social worker with expertise in HCT for individuals with IDD. Adolescents had visits every 3–6 months for transition planning, chronic condition management, and self-management goal setting prior to transfer between ages 19–21 (Fremion et al., 2017). Similarly in the complex care clinic, a hospital-based medical home clinic for children with complex medical conditions who are technology dependent, a physician, care coordinator, and social worker with HCT expertise met with adolescents aged 17 and older at least annually for transition planning until they transferred between ages 19–21. Finally, the time between the last visit from the referring pediatric clinic and the first visit to establish care in the adult clinic was documented to determine the interval of time between pediatric and adult care.

### Data analysis

Patient characteristics and survey responses were summarized using medians with minimum and maximum values, or frequencies with percentages. As the HCT Feedback Survey 2.0 does not have a total score, by consensus, the authors agreed upon a six-item composite outcome score based upon six questions that most closely matched questions from the NSCH 2019 Transition to Adult Health Care (Fig. 1). Independent logistic regressions were used to test the associations between meeting all six HCT criteria and patient characteristics. Factors found to be significant were considered for multiple logistic regression.

Additional outcomes evaluated were the level to which patients felt prepared to transition to adult care (categories: not prepared, somewhat prepared, and very prepared), and the time it took to transition to adult care as determined by the number of months between the referring pediatric clinic and the first visit with the adult care clinic. Independent proportional odds logistic regression was used to test the association between felt prepared and patient characteristics. A multiple regression was created using the factors that were significantly associated on independent regression. The proportional odds assumption was tested. Kaplan-Meier curves were used to summarize the number of months to transitioning to adult care. The median time between the last pediatric outpatient visit and the first adult IDD clinic visit (with 95% CI) was estimated for all patients and stratified by referral source. The log-rank test was used to determine if there was a difference in time to transitioning between referral sources, and if significant, pairwise log-rank tests with Holm's p-value adjustment were used to determine which referral sources were different from each other (Holm, 1979). Cox proportional hazards (CPH) regression was used to see if there was a difference in the time to transitioning between referral sources after adjusting for age at last pediatric visit (Cox, 1972). The proportional hazards assumption was tested.  $P < 0.05$  was considered statistically significant.

## Results

From November 2015 through December 2019, 406 YAIDD or their family members completed HCT feedback surveys, representing 65% of the 628 total new patient visits during this time. Patient characteristics

HCT Survey Questions Included:	Matching NSCH Questions
<ul style="list-style-type: none"> <li>• Did your previous healthcare provider informed you at what age you may need to transition? (Q. 4)</li> </ul>	<ul style="list-style-type: none"> <li>• Has your child's health care provider talked to you about seeing doctors for adults?</li> </ul>
<ul style="list-style-type: none"> <li>• Did your previous healthcare provider actively worked with you to gain skills to manage your health (some or a lot)? (Q.6)</li> </ul>	<ul style="list-style-type: none"> <li>• Has your child's health care provider actively worked to help your child make positive health choices and gain skills to manage health?</li> </ul>
<ul style="list-style-type: none"> <li>• Did your previous provider explained legal changes, decision-making, and consent changes that take place at age 18? (Q. 9)</li> </ul>	<ul style="list-style-type: none"> <li>• Has your child's health care provider worked with your child to understand changes in health care at age 18?</li> </ul>
<ul style="list-style-type: none"> <li>• Did your previous health care provider create and share with you a medical summary? (Q. 11)</li> </ul>	<ul style="list-style-type: none"> <li>• Did you receive a medical summary for your child?</li> </ul>
<ul style="list-style-type: none"> <li>• Did you know how you will be insured as an adult? (Q.13)</li> </ul>	<ul style="list-style-type: none"> <li>• Do you know how your child will be insured as an adult?</li> </ul>
<ul style="list-style-type: none"> <li>• Did your previous provider assist in identifying a new adult provider to transition to? (Q 15)</li> </ul>	<ul style="list-style-type: none"> <li>• Does your medical care plan address transition to health care providers for adults?</li> </ul>

Fig. 1. HCT satisfaction survey questions included in the composite criteria score with matching NSCH questions.

are summarized in Table 1. Spina bifida ( $p < 0.001$ ), Down syndrome ( $p < 0.001$ ), genetic/metabolic syndrome ( $p = 0.002$ ), autism ( $p < 0.001$ ) and diagnosis of ID ( $p < 0.001$ ) were associated with referral source (Table 2).

#### Factors associated with meeting all six composite HCT criteria

Referral source ( $p < 0.001$ ), spina bifida diagnosis ( $p = 0.001$ ), Down syndrome diagnosis ( $p = 0.013$ ), autism diagnosis ( $p = 0.032$ ), intellectual disability diagnosis ( $p = 0.032$ ), number of technologies required ( $p = 0.001$ ), race/ethnicity ( $p < 0.001$ ), and having private insurance ( $p = 0.043$ ) were significantly associated with meeting all six criteria of the HCT composite score. When these factors were included in multiple logistic regression, only referral source and race/ethnicity were significant (adjusted odds ratio in Fig. 2). Compared to patients referred from the community, those who were referred from the affiliated pediatric hospital (adj OR 1.97, 95% CI: 1.18–3.27) or from a designated HCT clinic (adj OR 10.24, 95% CI: 5.05–20.75) were more likely to have met all 6 criteria after controlling for race. Compared to Caucasians, Latinos (adj OR 1.82, 95% CI: 1.03–3.22) and African Americans (adj OR 3.30, 95% CI: 1.77–6.13) were more likely to have met all 6 criteria when controlling for referral source.

#### Factors associated with feeling prepared to transition to adult care

Using independent proportional odds logistic regressions, referral source ( $p < 0.001$ ), intellectual disability diagnosis ( $p = 0.035$ ), and the number of technologies required ( $p = 0.002$ ) were associated with the level at which patients felt prepared to transition to adult care. These significant factors were included in the final multiple proportional odds model and only the referral source was significant in this final model. Compared to patients who were referred from the community, the odds of feeling very prepared versus somewhat or not prepared was significantly higher among patients referred from a designated HCT program (adjusted OR 4.6, 95% CI: 2.38–8.83,  $p = 0.000$ ) whereas being referred from the pediatric hospital system was not significant (adjusted OR 1.44, 95% CI 0.86–2.39,  $p = 0.161$ ).

#### Comparison of time to establishing adult care between pediatric referral sources

The overall median time to transitioning to adult care was 5.1 months (95% CI: 4.3–5.8 months). Median times to transition to adult care by referral source are listed in Table 3. Patients referred from a designated HCT program transferred to adult care sooner than those who were referred from the community (median 2.7 vs. 5.3 months, pairwise log-rank test, Holm's adjusted  $p$ -value = 0.005), but there was no significant difference in time to transfer between referrals from the community versus the affiliated pediatric hospital (adjusted  $p$ -value 0.379). After adjusting for age at last pediatric visit, patients referred from a designated HCT clinic transitioned to adult care sooner than those referred from the community (adj HR 1.90, 95% CI: 1.41–2.55) as did those referred from the affiliated pediatric hospital system (adj HR 1.35, 95% CI: 1.05–1.74). However, after adjusting for referral source, older patients at the last pediatric visit transitioned to adult care sooner (per 1 year increase in age, adj HR 1.11, 95% CI: 1.07–1.15).

#### Discussion

This study of YAIDD establishing care with an IDD-specific adult medical home found that YAIDD transitioning from a designated HCT program were 10 times more likely to meet all six HCT criteria than those referred from a community referral source. Those referred from the affiliated pediatric hospital (external to the designated transition clinics) were 2 times more likely to meet all composite HCT criteria compared to those referred from the community. Those referred from a designated transition clinic were also 4.6 times more likely to feel very prepared to transfer to adult care than those referred from the community, whereas there was no difference in feeling prepared between YAIDD referred from the pediatric hospital system and the community.

The designated HCT clinics follow a structured approach to HCT designed to meet the Six Core Elements of HCT that includes discussing transition timing, setting goals for self-management, support to ensure adult insurance planning is in place at 18 prior to transfer to adult care, and tracking patients throughout the HCT process (McManus et al., 2015). Some aspects of this structured approach are implemented in

**Table 1**  
Summary statistics of survey respondents.

Age at adult medical home clinic first visit	N	Median [Min, Max]
	406	20 years [18.0,37.0]
Months between pediatric PCP and establishing adult care	346	5.1 months [0.0,101.4]
	N	(% out of 406)
Race		
Caucasian	136	(33.7)
Latino	138	(33.8)
African American	91	(22.3)
Asian	13	(3.2)
Multiracial	26	(6.4)
Unknown/Declined	4	(1)
Primary language		
English	340	(83.7)
Spanish	66	(16.3)
Primary insurance		
Private	138	(34.0)
Public (Medicaid or Medicare)	374	(92.1)
Active Home and Community-Based Waiver	200	(49.0)
Primary Diagnoses*		
Cerebral palsy	114	(28.1)
Spina bifida	55	(13.5)
Down syndrome	69	(17.0)
Genetic syndrome	77	(19.0)
Autism spectrum disorder	81	(20.0)
Other primary diagnosis	41	(10.1)
Diagnosis of intellectual disability	340	(83.3)
No technology dependence at the time of establishing care	207	(51.0)
Technology dependence		
Feeding tube	96	(23.6)
Tracheostomy	25	(6.2)
Ventilator	11	(2.7)
Wheelchair	164	(40.4)
Baclofen pump	20	(4.9)
Vagus Nerve Stimulator	14	(3.4)
Ventricular shunt	64	(15.8)
Referral type		(% out of 398)
Community	197	(49.5)
Affiliated children's hospital provider	132	(33.2)
Designated HCT Clinic	69	(17.3)

\* Total percentages are >100% due to patients potentially having more than one diagnosis.

the affiliated pediatric hospital system, which likely accounts for the differences in HCT preparation satisfaction seen. These findings highlight that HCT is a process requiring time and intentionality in preparing, coordinating hand-off, and ensuring that patients are established in the adult health care system. Structured HCT is particularly important for YAIDD who have both behavioral and medical complexity.

In this study, age was not significantly associated with meeting the composite criteria for HCT preparation satisfaction. In contrast, a study evaluating HCT satisfaction and readiness of adolescents and young adults with complex medical diagnoses (e.g. cystic fibrosis, sickle cell

disease, and solid organ transplants) found that older age and increased patient responsibility were significantly associated with increased HCT satisfaction and readiness (Haarbauer-Krupa et al., 2019). YAIDD population often have a delay in the acquisition of autonomous skills and/or still depend on parent caregivers throughout their adult life due to physical and/or cognitive disability which may account for age not being a significant factor in this study for HCT preparation satisfaction (Jacobson et al., 2018, Krell et al., 2021, Lennon et al., 2018).

Of the demographic factors examined, only race/ethnicity was significantly associated with having met composite HCT criteria after multiple logistic regression analysis. Latino and African American YAIDD were 1.9 and 3.3 times, respectively, more likely to meet all composite HCT criteria compared to Caucasian YAIDD. However, race/ethnicity were not significantly associated with feeling prepared to transition to adult health care. Race/ethnicity have variably been associated with meeting HCT outcome measures on serial analyses from 2001 to 2016 NSCH data (Lotstein et al., 2005; Lebrun-Harris et al., 2018; McManus et al., 2015; Lotstein et al., 2009a, 2009b). On secondary analysis of 2016 NSCH data, families of Latino patients with autism were more likely to report that their doctor did not spend enough time with them, and Latinos and African Americans were more likely to report that their doctor did not show sensitivity to their values and customs compared to Caucasians and Asians (Heron et al., 2020). While intervention studies addressing HCT racial/ethnicity disparities for YAIDD are limited, evaluating cultural and family values regarding emerging adulthood and care of the individual with IDD are important patient/family-centered HCT. Additionally, the impact of social determinant factors such as race/ethnicity on HCT and successful strategies to mitigate social determinant barriers via a structured HCT care model need to be further studied.

Finally, patients referred from a designated HCT program transferred to adult care sooner than those who were referred from the community (median 2.7 vs. 5.3 months). Older age was associated with a shorter interval of time between the last visit from the referring clinic and establishing with the adult clinic when adjusting for the referral source. In a recent study of young adults with spina bifida affiliated with the Spina Bifida Association, younger age was associated with already being established with an adult care provider (Stiles-Shields et al., 2021). The authors speculated that the increased prevalence of HCT programs over the last decade may account for their finding. These findings re-emphasize that having a structured HCT process to connect patients from the pediatric to the adult health care system is foundational to successful transfer.

*Practical implications*

HCT support for YAIDD often includes coordination for home health care, mental/behavioral health, supplies and equipment, adult disability determination and funding, guardianship or supportive decision-making, adaptive transportation, adaptive secondary education/employment, and community/independent living supports (Berens et al.,

**Table 2**  
Diagnosis stratified by referral source.

Diagnosis	Community (N = 97)		Affiliated Pediatric Hospital System (N = 132)		Designated HCT clinic (N = 69)		p-value*
	N	(%)	N	(%)	N	(%)	
Cerebral Palsy	51	(25.9)	45	(34.1)	18	(26.1)	0.250
Spina Bifida	9	(4.6)	1	(0.8)	44	(63.8)	<0.001
Down Syndrome	45	(22.8)	20	(15.2)	0	(0.0)	<0.001
Genetic Metabolic Syndrome	32	(16.2)	37	(28.0)	6	(8.7)	0.002
Autism	56	(28.4)	23	(17.4)	0	(0.0)	<0.001
Other Primary Diagnosis	19	(9.6)	16	(12.1)	5	(7.2)	0.551
Intellectual Disability	176	(89.3)	124	(93.9)	32	(46.4)	<0.001

\* p-values calculated with exact testing for categorical variables when possible otherwise chi-square test.

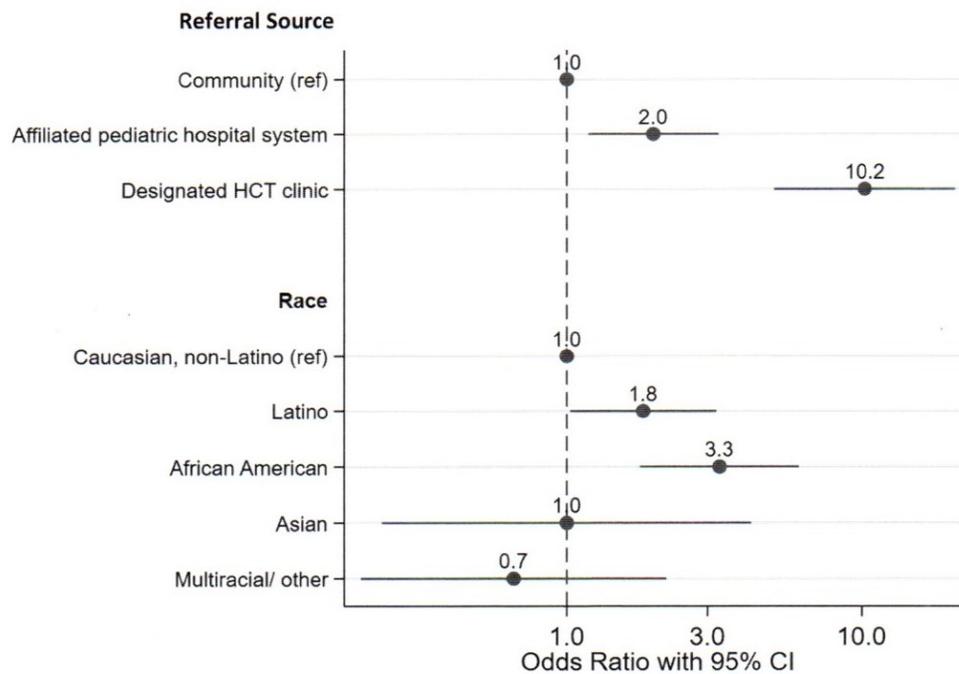


Fig. 2. Adjusted odds ratio for meeting all six HCT criteria.

2020; Cvejic & Trollor, 2018; Gauthier-Boudreault et al., 2017; Woodward et al., 2012). Addressing these specific needs often requires additional time and knowledge (Bolger et al., 2017; Gray et al., 2018). Similar to the positive impact of a designated HCT preparation program found in this study, Ciccarella et al. found that youth with IDD engaged in a multidisciplinary HCT clinic reported high levels of satisfaction in receiving HCT planning and care coordination supports (Ciccarella et al., 2015). Szalda et al. also described a hospital-wide implementation of a multidisciplinary team to address the multifaceted HCT preparation needs of youth with medical complexity and IDD wherein the multiple HCT planning concerns could be addressed and hand-off appropriate adult providers could be completed (Szalda et al., 2019). Not only do such comprehensive programs increase HCT planning for youth with IDD and YSCHN, but also may decrease costs. Maeng et al. demonstrated that YSCHN engaged in a comprehensive clinic to address transition coordination had decreased hospitalization and emergency department visits and thus decreased per-member-per month cost compared to those not engaged in this program (Maeng et al., 2017). These initial positive effects of IDD-specific HCT preparation services supports the further development and evaluation of these care models.

Transferring care to an adult provider can often be very emotionally stressful for YAIDD and their families. They may experience fear and apprehension about accessing needed services, understanding the transition process, and finding knowledgeable adult providers as well as the feeling of abandonment from the pediatric hospital system during HCT (Binks et al., 2007; Lariviere-Bastien et al., 2013; Young et al., 2009). Thus, minimizing care disruption during transfer to adult care is a goal

of HCT (American Academy of Pediatrics et al., 2002). In an international Delphi study determining indicators for successful transition, having the first adult care visit no later than 3–6 months after the pediatric visit was considered an important indicator of successful transition (Suris & Akre, 2015). Transferring to adult care within a shorter time interval may be particularly important for young adults with chronic conditions who require on-going medication, supply, equipment, and home service orders, and who need ready access to outpatient care to evaluate acute concerns and address care coordination needs. Having a close partnership between pediatric and adult health care may also facilitate a shorter transfer interval. Understanding how transfer time impacts acute care utilization (e.g. emergency room and inpatient visits) and unmet care needs for YAIDD is an area of further study.

Limitations

This study was completed in a large tertiary medical center where there is an established pediatric/adult care partnership for YAIDD, so generalizability may be limited. Only 65% of new patients during the study time completed surveys, in large part due to some new patients being transferred from other adult providers and not from pediatric care. The sample included patients who had successfully established with this specialized medical home for adults with IDD and did not include those who transitioned elsewhere or not at all. Similarly, only insured individuals were seen at the clinic; so, by definition, uninsured individuals were excluded. Moreover, HCT-related outcomes measured in this study are limited to the self-reported feedback survey and do not encompass other outcomes such as health status and acute care utilization, which were beyond the scope of this study (Gabriel et al., 2017; Schmidt et al., 2020). Of note, the HCT Feedback Survey 2.0 has no reported psychometrics. It should also be acknowledged that YAIDD or their families could choose to complete the survey. Future studies may evaluate differences between YAIDD and family satisfaction with HCT preparation as previous literature has shown variability between adolescent/parent reporting (Zabel et al., 2011). Additionally, unmet healthcare and community support needs such as education/employment supports, transportation, and housing that are often priority

Table 3  
Median time to transition to adult care by referral source.

	N	Median number of months	95% confidence interval	
Community	154	5.30	4.63	6.63
Affiliated Pediatric Hospital System	118	5.60	3.73	6.90
Designated HCT Clinic	69	2.73	2.10	4.53

concerns for YAIDD and their families were not evaluated (Berens & Peacock, 2015; Lin et al., 2015; Woodward et al., 2012). Thus, further multi-site, prospective research is needed to assess the generalizability of IDD-specific HCT supports and better understand how designated HCT programs in partnership with stakeholders such as payer, community educational/vocational, independent living, and advocacy organizations may mitigate social barriers and improve health outcomes. Future studies should also evaluate the relationship between number of HCT preparation visits and outcomes including satisfaction and time to transition.

## Conclusions

YAIDD require comprehensive HCT services to meet their nuanced medical, emotional, behavioral, independent living, and care coordination needs (Cheak-Zamora et al., 2013; Lin et al., 2015). This study demonstrates that a diverse population of YAIDD establishing with a medical home for adults with IDD benefit from designated HCT clinics that addresses IDD-specific, individualized HCT planning, care coordination, and self-management. Further research is needed to compare HCT models for YAIDD regarding cost/utilization, long-term population outcomes, and perception of HCT preparation.

## Declarations of Competing Interest

None for any author.

## Author's statement

Ellen Fremion -Conceptualization, Investigation, Methodology, Formal analysis, Project administration, Validation, Writing original draft.  
Rachel Cowley - Data curation, Writing original draft

John Berens -Methodology, Data validation, Writing review and editing

Kristen A. Staggers - Methodology, Formal analysis, Writing review and editing

K. Jordan Kemere, Judy Lu Kim, Elisha Acosta - Data validation, Writing review and editing

Cynthia Peacock - Conceptualization, Writing review and editing

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