Health Care Transition Services for Youth With Autism Spectrum Disorders: Perspectives of Caregivers

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abstract

BACKGROUND AND OBJECTIVE: This paper seeks to describe the experience of youth with autism spectrum disorder (ASD) in making the health care transition (HCT) to adult care.

METHODS: We surveyed 183 parents and guardians of youth with ASD, assessing the extent to which youth and families experienced and desired HCT services, their satisfaction with services, and obstacles to transition. Descriptive statistics were used to examine HCT measures and Fisher's exact and *t* tests assessed whether demographic or health measures were associated with service receipt. Any measures with a *P* value <.05 were included in a logistic regression model, with service receipt as the dependent variable.

RESULTS: The receipt of transition services was low overall, with rates for individual services ranging from 3% to 33% and only 60% of the sample receiving any transition service. Despite these low rates, a majority of respondents reported wanting services (73.3%–91.6%), and satisfaction for received services was high (89%–100%). Regression analyses showed depression to be the only variable significantly associated with service receipt. Youth who were identified by their caregivers as having depression experienced a higher rate of transition service receipt than those not identified as having depression.

CONCLUSIONS: Findings suggest that there is a great need to address the provision of HCT services for youth with ASD. Although families who received HCT services were generally satisfied, overall rates of service receipt were quite low, and those who were not provided with services generally desired them.

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There is strong evidence that many youth with special health care needs (YSHCN) experience significant difficulties in making the transition to adulthood.[1–8] The health care transition (HCT) to adult medical care is an aspect of this process that remains a particular problem for YSHCN.[2,5,6,8] Although research shows that YSHCN encounter high rates of unmet needs in terms of HCT preparation,[5,8] they also experience significant gaps in access to care, delayed care, and lack of insurance coverage during HCT.[2,6] Substantial challenges in identifying adult primary care providers (PCPs) or adult specialists to whom they can transition have also been documented.[9,10] The literature indicates that these transition processes may be especially difficult for youth whose special health care needs involve mental health, developmental disabilities, or intellectual disability.[11–13]

Youth with autism spectrum disorder (ASD), a group of highly prevalent, lifelong neurodevelopmental disorders characterized by deficits in communication, social interaction, restricted interests, and repetitive behavior, may be particularly susceptible to challenges related to the HCT process. One factor complicating the process for this population is the estimated high incidence of physical and psychiatric comorbidities,[14–28] which may require youth with ASD to transition to a number of adult subspecialists in addition to a PCP. As noted earlier, evidence indicates that finding adult providers is 1 of the primary obstacles faced by YSHCN undergoing the HCT. Additionally, many youth with ASD experience communication challenges and unusual sensory responses to environmental stimuli, which results in increased anxiety when the patient enters a new environment.[29–31] Visiting a new doctor's office may therefore create obstacles for youth with ASD that are not experienced by other groups of YSHCN. Compounding HCT challenges for many youth with ASD are the guardianship changes that occur during the transition period; these changes may alter a parent's ability to interface with the health care system on behalf of his or her child.

Despite the many potential barriers that youth with ASD may face during their transition to adult medical care, this population's experiences of HCT are not well understood. Nevertheless, the limited research that does exist on this topic indicates that these youth experience significant disparities. A study of youth with ASD from the National Survey of Children with Special Health Care Needs (NS-CSHCN) found that only 21.1% of youth received transition planning services overall. Additionally, only 14.1% had engaged in a discussion with a health care professional about shifting to an adult provider, less than half (40.4%) had spoken to a provider about the health care needs of adults, and less than a quarter (22.4%) had discussed retaining insurance coverage. The study also found that less than half of the youth were encouraged by a provider to take responsibility for their own health (45.3%). Lastly, for most of the transition-related items examined in this study, youth with ASD had lower percentages of service receipt than other YSHCN, suggesting that there is a greater need for these services among this population.[32]

Transition to adult services has been widely endorsed for many years. The American Academy of Pediatrics has long emphasized the importance of the transition process, with their 2002 consensus statement on transition defining its goal as a process to "maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood."[33] The Maternal and Child Health Bureau (MCHB) has also had a long-standing focus on transition to adulthood, beginning with the 1989 Surgeon General's conference on transition of YSHCN.[34] This emphasis continues today, with transition listed as 1 the MCHB's 6 core objectives.[35]

The current study aimed to address the gap between the endorsement of transition services and our knowledge about the transition process by surveying a large cohort of parents and guardians of youth with ASD. Specifically, this study sought to describe the extent to which youth and their families experienced and desired HCT services and their satisfaction with these services. We also aimed to identify obstacles to the transition process and to examine whether sociodemographic or health-related characteristics were related to obtaining transition services. This study provides new information on the use and satisfaction with services and a description of barriers to transitioning. We hypothesized that transition service receipt would be greater among youth with more need. Need was conceptualized as including several components that have been found to be indicators of greater dependence on the health care system among children, youth, and adults with ASD. Thus they are markers of youth for whom successful transition is most critical. The components of need were drawn from the literature and from the qualitative analyses.[32,36,37] These markers included ASD severity; behavioral, communication, medical, psychological, sleep, and other functional difficulties; health care and health care access; and child age, with older children being expected to have a greater need for transition-related services.

METHODS

Participants and Procedures

Study participants included parents and guardians of youth with ASD who were ages 13 to 26. Although the primary study team was based at Massachusetts General Hospital (MGH), study recruitment took place at 3 sites outside the MGH network. Subjects were recruited from 2 clinical sites in the Midwest, the University of Missouri's Thompson Center for Autism and Neurodevelopmental Disorders and the University of Cincinnati's Kelly O'Leary Center for Autism Spectrum Disorders, and from the Federation for Children with Special Needs (FCSN), a northeastern parent advocacy organization. Both Midwest recruitment sites are part of the Autism Speaks Autism Treatment Network, a clinical registry of 14 autism specialty care centers located across North America. These sites used their individual patient registries to identify and recruit eligible study participants. Eligible participants spoke English and had a child in the registry with ASD aged 13 to 26 years. The FCSN used their established electronic mailing lists to identify potential study participants. All patients from the FCSN who were interested in study participation were asked to contact the research team at MGH, where subjects were screened and enrolled in the study. Each study site's institutional review board provided approval for all aspects of the research.

Participation in the study involved the 1-time completion of a brief cross-sectional questionnaire designed by the study team. This self-report questionnaire assessed the extent to which youth and their families experienced and desired HCT services, their satisfaction with these services, and obstacles to the transition process. It also included items on sociodemographic and health status characteristics, as well as health service use data. At all study recruitment sites, parents were mailed or e-mailed the questionnaire, a recruitment letter, and an opt-out card and were asked to return their completed surveys or opt-out card. Nonresponders received a reminder phone call or e-mail. All subjects who returned completed surveys received a $20 gift card. The overall response rate was 61.3%. This response rate is the number of completed surveys divided by the sum of the number of families who sent the survey from the 2 Autism Speaks Autism Treatment Network sites plus the number of FCSN participants who responded to the electronic mailing list call for participants that they were willing to be part of the study (whether or not they returned a survey).

Measures

As noted earlier, the study questionnaire was designed by the study team at MGH and Brandeis University. Some of the questions were informed by qualitative interviews with pediatric and adult health care providers conducted by the study team as part of an overall project on HCT.[36–38] We also included the key HCT, sociodemographic, and health characteristics assessed on the NS-CSHCN, allowing us to make basic comparisons between our study data and that of the national survey. The survey was edited based on parent advisors' review of the draft survey. The specific content included in the survey is described in this section.

Sociodemographic, Health, and Health Care Use Characteristics

Youth sociodemographic characteristics assessed by the survey included child age, race, gender, and guardianship status. We also examined the youth's diagnostic subtype (autism, Asperger's, pervasive developmental disorder not otherwise specified, or other). ASD severity (mild, moderate, or severe) was based on caregiver report. The severity question came from the NS-CSHCN survey and asked respondents, "Would you describe [his/her] autism or ASD as mild, moderate, or severe?" The survey also assessed respondent-reported health and functioning problems that commonly accompany ASD, such as communication difficulties, depression, and gastrointestinal problems, and health care access, such as whether the youth had a personal doctor or nurse and the number of health care visits made in the past year. Special considerations for health care visits that the parent or guardian indicated were also assessed, such as the need for extended appointments and concerns about the use of extra nursing staff. (See Table 2 for a complete list of variables examined.) The survey additionally assessed the sociodemographic characteristics of the parent or guardian, including the respondent's relationship with the youth, the highest grade of school completed by the respondent, marital status, and family income.

HCT Characteristics

The majority of the survey's transition-related questions asked respondents whether they had received a specific HCT service from 1 of their child's health care providers. If the service had been received, the respondent was asked to rate his or her satisfaction with it. If the service had not been received, the respondent was asked to specify whether he or she would have liked to have received that service. We did not ask these latter 2 questions for 2 of the questions, and therefore the data are not available. The 9 specific HCT services included on the questionnaire are detailed in Table 3. These questions include domains found in the NS-CSHCN, domains identified in the qualitative part of the study (eg, finding an adult provider), and those that were identified in the qualitative interviews (eg, having a written medical summary). We were not

able to conduct psychometric testing on these items. In addition to these service-specific questions, the survey asked parents and guardians whether they had faced obstacles related to HCT. For a complete list of the specific obstacles assessed, see Table 4. These obstacle questions were based on information from the parent and provider qualitative interviews. Finally, the questionnaire asked respondents whether their child had completed the transition to adult health care and, if not, whether they thought that their youth was adequately prepared to make the switch.

Statistical Analysis

We first described the sociodemographic, diagnostic, and health characteristics of the youth and family, including means and percentages. Descriptive statistics were then used to examine participants' experiences of HCT services. Specifically, we tabulated the percentage of respondents who reported that they received a service, their satisfaction with the service, and those who did not receive a service but would have liked to receive it. Results were shown for the overall sample and by age group. We additionally tabulated percentages for specific HCT obstacles. Fisher's exact and *t* tests were used to examine if any sociodemographic (age, gender, health, or health care access) measures were significantly associated with receipt of transition services. Any measures with a $P < .05$ were included in a logistic regression model as independent variables, with service receipt status as the dependent variable. Service receipt status was created as a composite of the 10 service receipt questions. If any of the responses were "yes," then service receipt status was coded as yes. ASD severity, site, and whether a person feels prepared to make or has already experienced a HCT were also included as covariates in the model.

TABLE 1 Demographics of Youth and Parents

	%
N = 183	100
Youth age, y	
13–15	55.7
16–18	32.8
19+	11.5
Youth gender	
Male	87.4
Female	12.6
Youth race	
White	91.1
Other	8.9
Respondent's relation to child	
Mother	89.6
Other	10.4
Highest grade of school completed by respondent	
Less than high school diploma	11.6
High school diploma	28.7
College degree (2- or 4-y degree)	38.1
Postcollege degree	21.6
Marital status of respondent	
Single	10.4
Married or living with partner	72.1
Separated or divorced	17.5
Family income for last year	
$0–$24 999	19.8
$25 000–$49 999	19.2
$50 000–$74 999	25.4
$75 000+	35.6
Site	
Thompson Center for Autism and Neurodevelopmental Disorders	44.8
Kelly O'Leary Center for Autism Spectrum Disorders	16.9
FCSN	38.2

RESULTS

We surveyed a total of 183 parents and guardians of youth with ASD. The majority of these people were recruited from the autism specialty clinics in the Midwest, with 82 coming from the Thompson Center in Missouri and 70 from Cincinnati's O'Leary Center. The remaining 31 were recruited from the FCSN in Boston, MA. Table 1 shows the sociodemographic characteristics of the youth and their parents. Most of the youth were white (91.1%) and male (87.4%). This compares with 67.0% non-Hispanic white and 78.4% male for youth age 12 to 17 years from the NS-CSHCN 2009–2010.[32] The cohort had a mean age of 15.6 years; slightly more than one-half (55.7%) were younger adolescents (ages 13–15), one-third (32.8%) were between the ages of 16 and 18, and the remaining 11.5% were ≥19 years. Parent respondents were primarily mothers (89.6%) who were married or living with a partner (72.1%), had at least a 2- or 4-year college degree (59.7%), and had an annual family income of >$50 000 (61.0%).

Table 2 presents the diagnostic, health, and health care characteristics of the youth. The majority of the youth had a diagnosis of either autism or Asperger syndrome (83.5%) that was considered to be of mild (38.3%) or moderate (45.9%) severity. Other problems were found to be common, with >70% of the youth reported to have difficulty processing sensory information, difficulty communicating, and anxiety. Other commonly reported difficulties included problems with repetitive behavior (63.9%) or other behavioral problems (48.6%), sleep problems (42.6%), and difficulties

TABLE 2 Diagnosis, Health Characteristics, Issues and Difficulties, and Health Care Use

	% or Mean
ASD diagnosis	
Autism	40.9%
Asperger syndrome	42.6%
Pervasive developmental disorder not otherwise specified	15.3%
Other	1.14%
ASD severity	
Mild	38.3%
Moderate	45.9%
Severe	15.9%
Issues and difficulties	
Difficulty processing sensory information	72.7%
Difficulty communicating	72.1%
Anxiety	72.1%
Repetitive behaviors	63.9%
Other behavior problems	48.6%
Sleep problems	42.6%
Difficulty with digestion	41.5%
Disordered eating	39.3%
Depression	28.4%
Other health or functioning issues	21.3%
Current health insurance coverage	
No insurance	1.1%
Private	45.9%
Public	29.5%
Public and private	21.9%
Other	1.6%
Mean no. doctor or provider visits in last 12 mo	8.8
Have personal doctor or nurse	
No regular health care provider	2.7%
Primary care pediatrician	70.5%
Pediatric specialist	38.3%
Nurse practitioner	15.9%
Other personal doctor or nurse	27.3%
Mean no. visits with personal doctor or nurse in last 12 mo	4.8
Health care–related needs	
Scheduling appointments for a specific time or day	51.4%
Concerns about medication interactions	21.3%
Extra or extended appointments	14.2%
Doctor or nurse modeling steps to be performed in the examination	11.5%
Seen in a quiet secluded room or a private office	9.8%
Use of extra nursing staff	9.8%
Use of social stories or communication boards	8.7%
Visits to the doctor before a procedure to familiarize the patient	6.6%
Separate waiting room	5.5%
Augmentative communication	4.4%

with digestion (41.5%). Rates of health care access were also high among respondents. Although most of the youth were reported to have a regular health care provider (97.3%), the average number of doctor visits among the sample was 8.8 per year. Additionally, almost all youth were reported to have ≥1 type of insurance coverage (98.9%). Parents reported a variety of health care needs related to their child's ASD. The most common of these were scheduling an appointment for a specific time of day (51.4%), concerns about medication interactions (21.3%), and needing extra or extended appointments (14.2%).

In contrast to the high rates of insurance coverage and health care access reported in this sample, the receipt of transition services was generally low (see Table 3). Although rates for specific HCT services ranged from 3% to 33% for the overall sample, the services youth and families were least likely to be provided with included receiving a written transition plan (3.3%), support in searching for an adult PCP (7.3%), and a written medical summary (8.8%). Respondents were most likely to have had a discussion with a provider about how the youth's health care needs might change as he or she enters adulthood (33.3%), how to manage the transition into the adult health care system (19.8%), and how to teach the youth to manage their own health care needs (19.4%). Approximately 40% of the overall sample did not receive any of these transition services. In addition to showing service receipt characteristics for the overall sample, Table 3 includes rates of service receipt by age group (13–15, 16–18, and 19+ years). There was no clear pattern across measures in the level of service receipt by age group.

Despite low rates of service receipt, Table 3 shows that satisfaction for the services that were received was high, with nearly everyone reporting that they were somewhat or fully satisfied with the particular service being evaluated. Table 3 also shows the proportion of respondents who wanted a particular HCT service despite not being provided with it. These values ranged from 67% to 90%, with receiving informative materials about transition (90.4%), a written transition plan (87.2%), and a written medical summary (87.2%) being identified as the most desirable of the services evaluated.

Table 4 describes the obstacles faced by families in making the HCT. Just over half (51.1%) of families reported that they lacked information on the transition process. Other commonly reported obstacles included difficulty finding an adult PCP with sufficient ASD knowledge (31.3%), difficulty finding an adult PCP (29.1%) or medical specialist (21.4%) who is autism-friendly, and lack of

TABLE 3 Transition Services Receipt and Satisfaction

	% Received Service				% Satisfied With Received Service	% Did Not Receive Service but Would Have Liked To
Transition Service Assessed	Full Sample	13–15 y	16–18 y	19+ y	Full Sample	Full Sample
Provider discussed how health care needs might change in adulthood	33.3	29.4	38.3	38.1	N/A	N/A
Provider discussed how to manage child's transition into adult health system	19.8	16.7	25.4	19.1	N/A	N/A
Informative materials about transition process	17.0	19.6	13.6	14.3	100.0	90.4
Written transition plan	3.3	2.9	5.0	0	100.0	87.2
Written medical summary	8.8	10.9	8.3	0	100.0	87.2
Support in searching for an adult PCP	7.3	3.0	14.0	9.5	90.9	79.7
Information on adult medical specialists	11.8	9.0	15.8	14.3	94.4	82.0
Help with teaching youth to manage own health care needs	19.4	22.5	12.3	23.8	100.0	73.3
Information about obtaining guardianship	9.0	1.0	19.0	20.0	100.0	67.0
Other transition-related services or supports	13.3	5.9	24.1	19.1	88.9	N/A
Received any transition service	59.6	55.9	66.7	57.1	96.8	91.6

N/A, not available.

TABLE 4 HCT-Related Obstacles

Obstacles You Face or Have Faced in Making the Transition	% Yes
Lack of information on the transition process	51.1
Difficulty finding an adult PCP who is sufficiently knowledgeable about ASDs	31.3
Difficulty finding an adult PCP who is autism-friendly or willing to accept your child as a patient	29.1
Difficulty finding an adult medical specialist who is autism-friendly or willing to accept your child as a patient	21.4
Lack of coordination and communication between pediatrician and adult PCP	19.8
Difficulties related to insurance coverage	16.5
Difficulties related to guardianship	12.1

coordination and communication between providers (19.8%).

We also examined whether any sociodemographic, health, or reported difficulties were associated with the receipt of transition services. Table 5 shows the results of multivariate models that include variables associated at the .05 level or less in bivariate analyses. We found few characteristics to be associated with the receipt of care in bivariate models. In multivariate models, the only characteristic that was found to be significantly associated with receiving any transition service was depression (odds ratio = 2.7; 95% confidence interval, 1.2–5.9; P = .0112). Youth who were identified by their caregivers as having depression experienced a higher rate of transition service receipt than those not identified as having depression.

DISCUSSION

This study shows remarkably low rates of transition service receipt among a cohort of youth with ASD and their families. For example, 19.4% of respondents reported that the youth received teaching about managing his or her own health care needs, whereas in a national data set 45.3% of children with ASD and 73.5% of YSHCN reported that the provider encouraged the youth to take on appropriate responsibility for his or her health care needs.[32] Our results show that receipt for specific services ranged from 3% to 33%, with ~40% of the sample not receiving any HCT services at all. This result stands in contrast to the advocacy for transition services nationally by the American Academy of Pediatrics[33] and the MCHB.[34,35] In conjunction with these efforts, the Got Transition/Center for Health Care Transition outlines a model for a comprehensive set of best practice transition services.[39] These low rates of service receipt were coupled with high rates of respondents desiring services (despite not being provided with them) and high levels of health care access, insurance coverage, and income. The average number of health care visits for the sample was 8.8 per year, <3% of the sample reported not having a regular provider, and only 1% reported having no insurance.

TABLE 5 Receipt of HCT Services Among Youth With ASD ($N = 183$)

Variable	Any Transition Service Received, %	No Transition Services Received, %	Multivariate Model[a] Odds Ratios (95% CI)
ASD severity			
Mild	39.4	36.5	1.00
Moderate	42.2	51.4	0.74 (0.3–1.5)
Severe	18.3	12.2	1.39 (0.5–3.7)
Site			
Thompson Center for Autism and Neurodevelopmental Disorders	48.6	39.2	1.00
FCSN	14.7	20.3	0.83 (0.3–2.1)
Kelly O'Leary Center for Autism Spectrum Disorders	36.7	40.5	0.90 (0.4–1.8)
Feels prepared to or already experienced a transition			
Yes	27.5	15.9	1.90 (0.8–4.3)
Already switched	6.9	11.6	0.65 (0.2–2.0)
No	65.7	72.5	1.00
Depression	35.8[b]	17.6[b]	2.72 (1.3–5.9)[b]

CI, confidence interval.
[a] Multivariate models include variables that were statistically significant at the .05 level or less in the bivariate analyses.
[b] $P < .05$.

Our analyses found few sociodemographic, health, or health care access characteristics to be associated with the receipt of any transition service, with report of depression being the only association to hold up in multivariate linear regressions. Contrary to what we hypothesized, need characteristics, defined as greater ASD severity and higher child age, were not associated with greater receipt of transition services. These findings are surprising, considering that sociodemographic and health-related characteristics are often strong predictors of receipt of care. Nevertheless, Cheak-Zamora et al[32] had a similar finding, with family factors not serving as predictors of receipt of HCT services among youth with ASD. The relative lack of predictors in the bivariate and multivariate models, combined with low levels of service receipt, suggest that transition interventions must target all youth with ASD rather than specific subgroups.

Although many HCT obstacles were commonly reported by respondents, a lack of information about the HCT process was the most frequently cited obstacle. Similarly, receiving informative materials about transition was identified as the most desirable of all the transition services evaluated. These issues, along with teaching the youth about his or her changing health care needs, may be at least partially addressed by having providers give families informational packets about the HCT process during routine health care visits; reminder systems in electronic medical records might prompt provides to have transition-related conversations. Care coordinators could also support families in obtaining and using information. Such tools exist for children with special health care needs in general[40–42] and for youth with ASD specifically.[43] Linking these information tools to families may be an effective start in improving the transition process for youth with ASD and their families.

Respondents' second most commonly reported HCT barrier was difficulty finding an adult provider with sufficient knowledge about ASDs. A potential policy solution for addressing this obstacle is to improve education about ASDs and transition in medical schools, residency curricula, and continuing medical education courses. Specifically, curricula could be adjusted to teach pediatric and adult providers about ASD and the HCT process and to give clinicians guidelines on how to best facilitate the transition for their patients. "Got Transition," a cooperative agreement between the MCHB and the National Alliance to Advance Adolescent Health, supports this type of transition training for providers and suggests that all pediatric health care settings develop a transition policy.[39] The program's Six Core Elements initiative offers an outline for providers about how to transition a youth to adult care and is available online. Nevertheless, there are few evaluations assessing the impacts of provider education and training.[1] Additionally, even with improved education, providers have limited time to complete transition tasks and experience constraints related to caring for patients with complex needs because of the structure of the health care and payment systems.

This study has several limitations. First, the convenience sample was collected from a well-resourced group of families. This bias probably results from the recruitment of participants through clinics and an advocacy electronic mailing list. Despite this potential bias toward a high level of receipt of services, we saw low rates of transition service receipt. Although our sample is probably not generalizable to all families of children with ASD, we speculate that our data may represent a best-case scenario, which would indicate a great need for improved HCT services for a general population of youth with ASD. Second, we obtained responses from parents and guardians and not from youth themselves. We did so to ensure that we would have reliable data from all families, regardless of the youth's ability to communicate.

Third, these data do not show the perspectives of providers. Perhaps the low levels of HCT service receipt are related to expectations on the part of providers that these services would be provided through the educational system. Future studies of the provider perspective could point to possible solutions. Fifth, our measurement of HCT did not undergo formal psychometric testing. Lastly, youth with ASD are experiencing other transitions during their teenage and young adult years, which could influence the HCT process. For example, many youth experience transitions related to their living situation or education. However, addressing how these other transitions might affect experiences of HCT was beyond the scope of this study.

Our findings suggest that there is a great need to address the provision of HCT services for youth with ASD. Although families who have transition services are generally satisfied with them, overall rates of service receipt were low, and those who were not provided with transition services generally desired them. We also found that many parents reported obstacles to obtaining these services, with a particular desire for more information on the transition process and adult providers who could better meet their needs.

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ABBREVIATIONS

ASD: autism spectrum disorder
FCSN: Federation for Children With Special Needs
HCT: health care transition
MCHB: Maternal and Child Health Bureau
MGH: Massachusetts General Hospital
NS-CSHCN: National Survey of Children With Special Health Care Needs
PCP: primary care provider
YSHCN: youth with special health care needs

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