

Final Comprehensive Report

I. INTRODUCTION

A.) Nature of the research problem:

Research indicates that few adolescents with special health care needs receive services to help them transition to the adult health care system. The Health Care Transition (HCT) to adult care is likely to be especially challenging for youth with Autism Spectrum Disorders (ASD), who may experience medical co-morbidities and unusual sensory responses that make their adult health care needs particularly complex. As a result, youth with ASD are often underserved when it comes to health care. With the increase in ASD prevalence, the lack of care continuity may create significant and long-lasting challenges to the health care system and related systems, such as residential care and social services.

B.) Purpose, scope and methods of the investigation:

This study sought to better understand the Health Care Transition (HCT) process for youth with ASD and to uncover best transition practices. We additionally aimed to design a preliminary HCT-focused intervention and to examine the plausibility and feasibility of this model. To accomplish our first aim, we conducted extensive interviews with pediatric providers at sites of the Autism Treatment Network (a group of 17 autism specialty clinics located across the U.S. and Canada), other autism specialty clinics, and primary care offices. We additionally interviewed adult providers of young adults with ASD, and surveyed a large cohort of parents about their HCT experiences. To accomplish our second aim of designing a preliminary intervention, we conducted an analysis of Aim I data and developed a logic model for achieving transition for all youth with ASD. We then targeted one of the key activities identified in the logic model and created a repository of training materials on transition for adult providers.

C.) Nature of the findings:

We used both qualitative and quantitative methods to analyze the data collected.

II. REVIEW OF THE LITERATURE

There is strong evidence that many Youth with Special Health Care Needs (YSHCN) experience significant disparities in making the transition to adulthood.³⁻¹⁰ The Health Care Transition (HCT) to adult medical care is an aspect of this process that remains a particular problem for YSHCN.^{4,7,8,10} While research shows that YSHCN encounter high rates of unmet needs in terms of HCT preparation,^{7,10} they also experience significant gaps in access to care, delayed care, and lack of insurance coverage during HCT^{4,8} and substantial challenges in identifying adult primary care providers (PCP) and/or adult specialists to whom they can transition.^{11,12} 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 disabilities.¹³⁻¹⁵

Youth with an Autism Spectrum Disorder (ASD), a group of pervasive developmental disorders characterized by deficits in communication and social reciprocity and restricted interests and repetitive behaviors, may be particularly susceptible to challenges related to the HCT process. One factor complicating HCT for this population is the high incidence of physical and psychological co-morbidities.¹⁶⁻³⁰ These conditions may make individuals' adult health care needs particularly complex and require transitioning to adult subspecialists in addition to a PCP. Further compounding HCT challenges for many youth with ASD are their communication challenges and unusual sensory responses to environmental stimuli, such as hypersensitivity to touch during examinations and increased anxiety associated with entering new, stimulating environments.³¹⁻³³ Many adult providers may be unwilling or unable to accept patients with these particular sensory challenges. Lastly, youth with ASD may undergo guardianship changes during the HCT process. This may change parents' ability to interface with the health system on behalf of their child, further complicating the HCT process. One study using data from the National Survey of Children with Special Health Care Needs (2005-2006) examined the use and predictors of transition services for youth with ASD.³⁴ This study showed low levels of transition planning, with only 21.1 percent of the sample receiving transition planning services overall. The receipt of services was defined as having a discussion with a provider about each of the following topics: shifting to an adult provider (14.1%), health care needs of adults (40.4%), health insurance retention (22.4%), and taking responsibility for his/her own health

(45.3%). All of these percentages were lower for youth with ASD than they were for other YSHCN with the exception of the adult health insurance discussion, which was about the same low percentage in both groups.³⁴

Despite the many potential challenges that youth with ASD may face during their transition to adult medical care, this pediatric population's experiences of HCT and their satisfaction with the process is not well understood. The present study addressed this knowledge gap by evaluating the experiences of youth with ASD and their families as well as those of pediatric and adult providers.

III. STUDY DESIGN AND METHODS

A.) Study design:

This study sought to better understand the Health Care Transition (HCT) process for youth with ASD and their families and uncover best transition practices. We additionally aimed to design a preliminary HCT-focused intervention and to examine the plausibility and feasibility of this model. Specific goals for Aim I included: 1.) determining the HCT services provided at sites of the Autism Treatment Network (ATN), other autism specialty clinics, and 2 primary care offices; 2.) describing the characteristics that adult providers identify as important in their willingness to care for young adults with ASD; and 3.) gaining an understanding of families' exposure to HCT services, their use of these services and predictors of parent satisfaction. We employed several different methods to accomplish these goals. To determine the state of HCT services at ATN sites, other specialty clinics and primary care offices, we conducted extensive interviews with the pediatric providers at these sites who were most knowledgeable about the transition process. We then conducted in-depth site studies at the 3 specialty clinics that exemplified best practices. This work involved interviewing additional pediatric providers, administrators, and parents whose youth were patients at these clinics. To obtain perspectives from adult providers, we conducted extensive interviews with adult PCPs and specialists who care for young adults with ASD. We lastly surveyed a large cohort of parents of youth with ASD about their HCT experiences.

The second aim of this study was to design a preliminary HCT-focused intervention. Specific aims included: 1.) developing a logic model of "best practice" transition services; 2.) assessing whether the outcomes were likely to be achieved given the program's time frame, resources, activities, and context; and 3.) assessing the likelihood that the innovation could be fully implemented in different settings. This work first involved analyzing Aim I data to determine the most prevalent HCT issues. Finding there to be a significant lack of adult providers for youth with ASD to transition to, we targeted one key activity in our logic model; that of sharing educational resources on transition with adult providers. We worked with Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and the Association of University Centers on Disability (AUCD) to assess the current state of adult provider training materials. Specifically, we surveyed 11 LEND program directors and conducted in-depth interviews with 9 LEND professionals and adult med-peds and family medicine physicians. We then used the LEND network to collect existing adult provider training resources (PowerPoint presentations, modules, online courses, etc.), reviewed these materials (14 in total) and eliminated those that weren't entirely relevant. We lastly created a repository of the most relevant training resources in partnership with the AUCD (6 in total) and shared these materials via the AUCD website transition toolbox..

B.) Population studied:

This study focused on youth and young adults with ASD and their families, as well as the pediatric and adult providers who serve this population.

C.) Sample selection:

1. Pediatric and adult providers of children with ASD:

We recruited 55 providers in total. The vast majority of pediatric providers were recruited from ATN sites and other specialty clinics, but two were from primary care clinics. Respondents included physicians, psychologists, social workers, and registered nurses or pediatric NPs. Adult providers were recruited through the use of purposive and snowball sampling techniques. We obtained many of our initial adult provider contacts through referrals from the ATN.

2.) Parents of children with ASD:

We recruited 194 parents/guardians of a youth with ASD age 13 or older. The vast majority of these subjects were recruited from a Northeastern parent advocacy organization and two ATN clinics located in the Midwest. The remaining parent participants were interviewed as part of our in-depth site studies.

D.) Instruments used:

1.) Interview guides for pediatric and adult providers:

We developed an interview guide to ask ASD-experienced pediatric providers about their site's current HCT strategies, barriers to transition, connections with adult providers and other relevant site characteristics. This guide also assessed which HCT strategies providers felt were most needed (but not necessarily in place) and how the transition process could be improved. We also developed an interview guide for adult physicians of young adults with ASD (PCPs and specialists) to identify what was most important in their decision and ability to care for this population. This guide additionally asked providers about their experience and background with ASD, the characteristics of their practice, interactions with other medical providers and care coordination. We lastly asked adult providers' about strategies for increasing the number of adult physicians who are ready and able to provide care for adults with ASD.

2.) HCT survey for parents of children with ASD:

We designed a survey to capture the extent to which youth and their families experienced HCT services, the extent to which they desired services, and their satisfaction with services. The survey also aimed to identify HCT barriers and examine whether health and socio-demographic characteristics were related to obtaining and wanting HCT services.

E.) Statistical techniques employed:

1.) Pediatric and adult provider data: the framework approach

We analyzed the interview data collected from pediatric and adult providers using the framework approach.^{39,40} This is a nuanced approach to analyzing qualitative data that was designed specifically for applied policy research. The framework approach has many similarities to thematic analysis,⁴² but emphasizes transparency in data analysis as well as the links between each of the stages of the analysis. It relies on three inter-connected stages that require the research team to explicitly describe the processes that guide the systematic analysis of data from initial management through to the development of descriptive accounts and explanatory accounts.^{40,43} (See Smith and Firth (2011) for a detailed example of this three-stage framework approach.) Our analysis followed this 3-stage approach. In the 1st stage of analysis, *Data Management*, two members of the research team who had conducted the interviews became more familiar with the data by reading the transcripts several times. A set of initial categories and themes were identified using the respondents own words as a means of staying true to the data.⁴³ In the 2nd phase of analysis, *Descriptive Accounts*, two different members of the research team reviewed the transcripts and began to refine the initial categories. To ensure rigor, each researcher independently coded the data into the refined categories, discussed discrepancies, and reached consensus. In the 3rd and final phase, *Explanatory Accounts*, researchers examined the data further to identify associations or patterns within or across categories, further refining the original categories.

2.) Survey data:

We ran descriptive statistics on all survey data collected. We first described means and percentages for demographic and family information, as well as for diagnosis and health care utilization. We then described the percent of respondents who reported that they received a service, their satisfaction with the service, and the percentage of those who did not have a service but would like to receive it. We further described percentages for overall exposure to HCT services and reported obstacles families face in making the transition. We used Fisher's Exact and t-tests to determine if any demographics or health care utilization measures were significantly associated with the receipt of transition services in bivariate regression analyses. Any demographics or health care utilization measures with $p < 0.05$ were included in a logistic regression model as independent variables, with service status as the dependent variable.

3.) Intervention data:

We used data collected in the first phase of the study (Aim I) and input from ASD experts to create a logic model for achieving transition for all youth with ASD. We then targeted one of the key activities identified in the logic model and gathered existing training materials on transition for adult providers. (Please see the Appendix to view this logic model.)

IV. DETAILED FINDINGS

A.) Pediatric and adult provider data:

1.) Findings from interviews with pediatric providers:

Seven different interventions were identified as *needed* by providers (but not currently in place) and 5 different interventions were identified as *currently in practice*. Among those activities identified as *needed*, the 3 strategies

mentioned most frequently were: written materials for the family and clinician (e.g. individualized transition plan, care binder, medical summary, etc.), trainings for adult providers, and information sessions for families and youth. The activities most commonly identified as *in practice* included medical summaries, care coordination and the provision of resource links (e.g. list of adult providers, community resources, etc.). The most common in-place interventions were being used at 4 to 8 sites. (Full details on needed and in-place activities/interventions are provided below in Table 1).

All of the interventions identified as *currently in place* are operating within the pediatric practice. Among the *needed* interventions, 3 would operate within the pediatric practice and two would be implemented outside the pediatric practice. The remaining 2 desired strategies would be implemented both within and external to the pediatric practice (see Table 1). Many of the strategies that were identified as in place at some practices were identified as needed by other others.

Table 1. Transition Strategies or Interventions by Implementation Status and Location

Implementation Status	Location					
	#	Pediatric Practice Focused	#	External to Pediatric Practice	#	Internal and External to Pediatric Practice
Strategies or Interventions Needed	9	Written Materials (Care Binder, Workbook, Notes)	6	Training Adult Providers	4	Care Coordination
	6	Education/Training for Families & Youth (Information sessions, workshops)	3	Training Medical Students	4	Transition Center
	5	Creating Resource Links (List of providers, community resources)				
Strategies or Interventions in Place	8	Medical Records/summary				
	8	Creating Resource Links				
	5	Care Coordination				
	5	Transition-specific Appointments/Individual discussions with families and youth				
	4	Checklists				

2. Findings from interviews with adult providers:

We found two major categories of themes in our analysis of the adult provider interview data: 1.) Challenges to Providing Care and 2.) Solutions and Interventions. While the first category includes the various difficulties that providers face in caring for young adults with ASD, the second includes ideas and strategies to address such challenges. We additionally identified three subcategories within those two broad categories: A) Systems Level, B) Practice/Provision Level and C) Training & Education Level. These subcategories represent the level or arena in which the challenge, solution or intervention is taking place. Table 2 presents the specific challenges and solutions that adult providers discussed and places them in the relevant subcategory.

Table 2: HCT Challenges and Solutions identified by Adult Providers

	Systems Level	Practice/ Provision Level	Training & Education Level
Challenges to Providing Care	<ul style="list-style-type: none"> -Shortage of Services & Supports -Financial disincentives -Lack of adult providers -Time & Reimbursement 	<ul style="list-style-type: none"> -Time constraints and inefficiency -Complexity of family involvement -Physical Environment -Communication barriers 	<ul style="list-style-type: none"> -Lack of formal education and training
Solutions and Interventions	<ul style="list-style-type: none"> -Providing financial incentives, resources, & supports to providers, families, and individuals with ASD 	<ul style="list-style-type: none"> -Customized lists of resources and services -Reviewing patient lists frequently -Facilitating communication families & physicians -Enhancement of physical environment 	<ul style="list-style-type: none"> -Increased awareness -Early exposure to ASD population -Set expectation of provision of care -Provide broad-based training early and often for physicians and staff

B.) Survey data:

Overall exposure to transition services was gauged by the following questions: 1.) “Has your child’s provider talked to you about how his/her health care needs may change in adulthood?”, and 2.) Has your child’s provider talked to you about how to manage his/her transition into the adult health care system?” Of the 184 parents surveyed, a relatively small percentage answered yes to either of these questions. While only about one-third of the sample had discussed how their child’s health care needs might change in adulthood, only a fifth had had a conversation about how to manage the health care transition. Parents of children age 16 or older and parents of children with severe ASD were more likely to answer yes to both exposure questions. For full details on these transition exposure results broken down by age and ASD severity, please see Table 3 below.

The most common HCT services parents/youth received were: 1.) help teaching child to manage his/her own health needs (19%) 2.) informative materials about transition process (17%), 3.) other transition-related services or supports (13%), and information on guardianship (9%). The services that participants said they *would most like to receive but don’t currently receive* were: 1.) informative materials about transition (90%), 2.) a written transition plan (87%) 3.) a medical summary (87%), and 4.) support in searching for an adult specialist (82%) or PCP (80%). (Please refer to Table 4 below for more information on parents’ received and desired services.) Of the parents who received at least one transition service, about 52% identified themselves as neither satisfied or nor dissatisfied with their *overall* experience of services (e.g. “neutral”), while only about 22% identified themselves as satisfied *overall* (“somewhat satisfied” or “very satisfied”). Parents reported the biggest obstacles to transition to be: 1.) a general lack of information on the transition process (51%), 2.) difficulty finding an adult provider who is knowledgeable about ASDs (31%) and 3.) difficulty finding an adult provider who is ASD-friendly (29%). Of the 184 parents surveyed, 23% reported that their child was adequately prepared to make the switch to adult health care and 68% reported that their child was not. The remaining 9% had already made the transition to adult care. Table 5 shows the answer to the question: “Is your child adequately prepared to make the switch to adult health care?,” stratified by age and severity.

In further analyses, we found very few socio-demographic and autism-related characteristics to be associated with the receipt of care. *The only characteristics that were associated were reports of youth anxiety and reports of youth depression.* In both cases, symptoms were significantly associated with being more likely to receive transition services. When both of the above statistically significant variables (reports of youth anxiety or depression) were included in a logistic regression model, the depression finding remained statistically significant with 2.3 times the odds of receiving transition services when compared to those youth without depression (CI 1.150-4.714 p=.019).

Table 3: Overall Exposure to Transition Services by Child Age and Severity

	All Data	AGE			ASD SEVERITY		
		13-15 yrs	16-18 yrs	19+ yrs	Mild	Moderate	Severe
Provider discussed how health care needs may change in adult hood?	33%	29%	38%	38%	33%	29%	48%
Provider discussed how to manage transition into adult health care system?	20%	17%	25%	19%	19%	17%	31%

Table 4: Services Received vs. Services Desired

Transition Service	% Who Received Service	% Who Did Not Receive Service but Would Like to
Informative materials about transition process	17.1	90.4
Written transition plan	3.3	87.2
Written medical summary	8.8	87.2
Support in searching for an adult PCP	7.3	80.0
Info. on adult medical specialists	11.	82.0
Help w/ teaching child to manage own health care needs	19.4	73.3
Info. about obtaining guardianship	9.0	67.0
Other transition-related services or support	13.3	N/A

Table 5: Preparedness for Transition by Child Age and Severity

	All Data	AGE			ASD SEVERITY		
		13-15 yrs	16-18 yrs	19+ yrs	Mild	Moderate	Severe
Yes, child is adequately prepared to make switch to adult health care	23%	18%	30%	25%	26%	18%	29%
No, child is not adequately prepared to make switch to adult health care	68%	77%	65%	40%	66%	74%	57%
Child already made switch	9%	5%	5%	35%	8%	8%	14%

C.) Intervention data:

Interviews with LEND professionals and adult physicians and a careful review of existing training tools led us to recognize that some innovative resources focused on transition are in existence for adult providers, but that they tend not to be widely known or distributed. We also learned that these resources vary significantly in terms of format and

include online courses, toolkits, guidelines and PowerPoint presentations. Although we carefully reviewed all the training materials that were sent to us (14 in total), we eliminated those that weren't entirely relevant to the HCT process, leaving us with six training resources in total. These 6 resources were sent by 5 transition professionals and included four PDFs (articles, toolkits, and guidelines) and two PowerPoint presentations. These resources more than doubled the pool of training materials available via the AUCD website's transition toolkit.

V. DISCUSSION AND INTERPRETATION OF FINDINGS

A.) Conclusions, Implications, Next Steps, and Possible Applications to MCH Health Care Delivery:

1.) Pediatric providers:

Findings suggest that there seems to be some consensus about strategies needed to aid youth with ASD as they transition to the adult care system that are feasible and valuable across sites. For many of the interventions providers identified as needed, there was at least one example of a practice currently using the strategy. However, current, viable strategies were developed independently of one another, indicating that there are opportunities to share these resources with other providers who work with youth with ASD, and apply versions of these strategies to children with other conditions or CSHCN in general. Additionally, interventions identified as needed could be informed by generating discussions across sites. For example, practices that have already established resource links, such as lists of adult providers who serve youth with ASD, could be used as models or be paired with other pediatric practices, which may engender the sharing of information more broadly. A reasonable next step would be to create ways to disseminate transition resources and ideas and train other providers to use them.

While results suggest there are some promising strategies, one surprising finding remains; even amongst a group of pediatric providers who are regarded as experts in caring for individuals with ASD, there is relatively little being done in terms of interventions and strategies toward facilitating successful transition from pediatric to adult health care for youth with ASD. One explanation may be that providers and families face many significant challenges, including lack of government funding to support further development, testing, and implementation. These efforts are needed and would be consistent with health care reform efforts, Healthy People 2020, and medical home initiatives. Providers noted that they needed to find activities that were both feasible in terms of funding and capacity, as well as being productive as initial efforts to promote health care transitions for youth with ASD. For example, information sessions for families and youth could be done at a relatively low cost by using existing transition materials and might be successful as on-line training as well. Practices also identified a few interventions as needed that were not currently in place within any other practices or external to those practices, such as transition centers, training for providers, and training for medical students, suggesting a major gap in the provision of services and general medical training curriculums. Trainings for adult providers may involve a bigger investment (especially if they are associated with some sort of accreditation), although once a training program exists, the time and monetary cost of using it may be modest. Adult providers engage in ongoing learning in a variety of venues such as grand rounds and continuing medical education. If trainings about ASD and the care of young adults with ASD could be incorporated into these existing venues, the information could be readily available and well used.

In general the transition activities identified in this study (both in place and desired) mapped fairly directly to some of the core elements outlined by the National Health Care Transition Center but not to others (www.gottransition.org). The strategies and interventions described relate to the core elements of transition preparation (e.g., individual discussions with families and youth and information sessions and workshops), planning (e.g., medical summaries and checklists), and transfer of care (e.g., care coordination and resource linkages). However, among the six core elements of health care transition, no site mentioned writing and posting a transition policy or having a youth or adult registry of youth who will soon transition or who recently transitioned. In addition, the desire for more training of providers and medical students is not part of the six core elements.

With large numbers of youth with ASD becoming young adults, it seems that pediatric practices may want to consider some of the HCT activities endorsed and described here. Our work suggests that there are some relatively simple starting points for practices and that these have been successfully implemented and are viewed as useful. For example, family educational seminars and care binders, are likely relatively easy for a practice to implement. Others, such as increased training of adult providers, may be beyond the scope of most pediatric practices and would require a system-based intervention. Our findings additionally indicate that many current transition needs may be successfully addressed through the creation and sharing of materials, such as workbooks, toolkits, trainings (both online and in-person), and the devisement of a mechanism to widely distribute information. Such information may also benefit

families of individuals with other types of disabilities or special health care needs as well as the providers who serve these populations.

2. Adult providers:

The number of adults with ASD who need medical care from physicians trained to care for adults is rapidly increasing. However, few youth with ASD receive services to ease the transition from the pediatric health care system to the adult health care system. Our findings indicate that incentives, services, and supports are needed at the systems level to encourage adult providers to accept and feel comfortable working with patients with ASD. Opportunities for sharing information and expertise through reforms in Health IT should be investigated. Furthermore, innovations and interventions at the practice/provision level need to be implemented and tested and effective solutions need to be disseminated. Finally, at the training and education level, the situation calls for strategies to increase the size of the workforce of physicians interested and experienced in providing care to adults with ASD. Systematic training within residency programs and easily accessible training materials are potential ways to address the workforce capacity issue. Our findings indicate that isolated pockets of existing innovative training programs and curricula need to be shared and implemented more widely and that opportunities for education and training must be created through interagency coordination efforts. Early and positive exposure is critical to increase workforce capacity. Taken together, these findings suggest that several changes coming under health care reform could support providers' efforts to address the needs of adults with ASD.

3.) Parents of youth with ASD:

This data showed remarkably low rates of HCT service receipt. Rates of receipt ranged from 3.3% of families having a written transition plan to 19.4% percent reporting that they had help teaching their son/daughter to manage their own health care needs. These rates are relatively consistent with the data from a nationally-representative survey, showing that only 21% of patients met the criteria for having received transition services.* The four-question transition measure showed the service most likely to be received was providers encouraging youth to be responsible about their care (45%). These low rates of receipt of individual services are coupled with very high rates of respondents wanting to receive each service. Our data shows these rates to range from 90% of families wanting informative materials about the transition process to a low of 73% of families reporting that they would like help teaching their child to manage his/her own health care needs.

While many barriers were commonly reported by parents, lack of information was the most frequently reported barrier to HCT. This barrier, along with teaching the child about the child's health care needs, may be at least partially addressed by providing information on navigating the HCT process. Such tools exist for CSHCN in general and for youth with ASD specifically. Linking existing tools to families and assuring that they contain the correct information in a usable format may improve the transition process. On the provider side, a potential policy solution is improving medical and continuing education to teach both pediatric and adult providers about the transition process and to give providers guidelines on how to best facilitate the transition process for their patients. "Got Transition," the MCHB funded center for transition services, suggests that pediatric health care settings develop a transition policy and that both adult and pediatric care providers regularly assess youth's transition readiness and conduct transition planning activities. On the adult provider side, educating adult providers about caring for young adults with ASD may improve their knowledge about ASD, their willingness to care for patients with ASD, and their ability to provide care that is more autism-friendly. Other obstacles, such as barriers to finding adult providers (primary care or specialists) who are willing to accept the child as a patient, may be more difficult to address. Increasing the amount of education that providers receive in medical school, residency, and continuing medical education on caring for youth and adults with ASD may foster the skills and confidence to want to care for patients with ASD. Furthermore, structural barriers related to the time providers have for each appointment, payment to providers for caring for patients with complex needs, and barriers between providers and payments for physical and mental health may also contribute to the provider's ability and willingness to care for this population.

Our findings suggest that there is a great need to address the provision of HCT services for youth with ASD. A relatively low percentage of families are receiving HCT services and families who do not have them generally want them. We further found that parents reported barriers to obtaining these services at high levels, with a particular desire for more information and adult providers who could better meet their needs.

4.) Intervention design:

Our experience in creating the logic model, surveying experts in the field for examples of training materials focused on transition, and building a repository of training materials, highlighted the nascent and uneven state of knowledge around transition training for adult providers. Further work is needed to track the use of the repository materials and to further build the toolbox with revised, updated, and new resources.

B.) Explanation of study limitations

This study had several limitations. First, in terms of the data collected from pediatric and adult providers, the majority of our interviews were drawn directly from the ATN or originated in an ATN referral. This indicates that our findings are specific and targeted and somewhat limits their applicability. Additionally, our research was focused on identifying the state of transition activities across sites as opposed to extensive examinations of single sites. This limited our ability to examine the role of different providers and staff in integrating transition activities, which is likely be an important part of the HCT process. Further, our data only reflects the types of intervention strategies that providers are using or designing relative to transition. We did not gather data on the consistency with which these interventions were utilized in the sites or on their general effectiveness; both of these variable have the potential to enrich our understanding of the current state of the HCT process. This study also had limitations in terms of the survey data that we collected from parents of youth with ASD. First, the convenience sample was collected from three sites and is a relatively well-resourced group of families. Our data therefore may represent a best-case scenario, which would indicate a serious gap and great need for HCT services for youth with ASD. Despite this potential bias towards high service receipt, we saw low levels of the use of specific HCT services. Second, slightly more than half of the respondents' children were young adolescents ranging in age from 13-15 who are likely at the early stages of the transition process.

C.) Suggestions for further research:

Our findings support the need for further research in three specific and critical areas; (1) assessing ways to increase the workforce of adult providers able and interested in caring for youth with ASD; (2) evaluating practice-based strategies that enhance transition; and (3) examining ways to promote the self-determination skills of YSHCN so they participate in the transition process.

VI. LIST OF PRODUCTS:

A.) Conference Presentations

- 1.) Warfield ME, Kuhlthau K, Crossman M, Delahaye J, van der Weerd E. Integrating multiple perspectives on transition to adult health care for youth with ASD: where do we go from here? Oral presentation at: Combating Autism Act Initiative (CAAI); May 2013; Arlington, VA.
- 2.) Kuhlthau K, Warfield ME, Crossman M, Delahaye J, van der Weerd E. Transition to adult health care for youth with Autism Spectrum Disorders: issues and promising new directions. Poster presented at: Society for Research in Child Development Themed Meeting: Transitions from Adolescence to Adulthood; October 2012; Tampa FL.
- 3.) Crossman M, Kuhlthau K., Warfield ME, Delahaye J, van der Weerd E. Perspectives of adult physicians on providing care for adults with Autism Spectrum Disorders. Poster presented at: 46th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities; March 2013; San Antonio TX.

B.) Submitted Manuscripts:

- 1.) Kuhlthau K, Warfield ME, Hurson J, Delahaye J, Crossman M. Pediatric providers' perspectives on the transition to adult health care for youth with Autism Spectrum Disorders: current strategies and promising new directions. Submitted to: *Autism*. 2013.
- 2.) Kuhlthau K, Warfield ME, Delahaye J, Shui A, Crossman M van der Weerd E. Health care transition services for youth with Autism Spectrum Disorders. Submitted to: *JAMA Pediatr*. 2013.
- 3.) Warfield ME, Crossman M, Delahaye J, Kuhlthau K. Perspectives of adult physicians on providing care for adults with Autism Spectrum Disorders. Submitted to: *Soc Sci Med*. 2013.

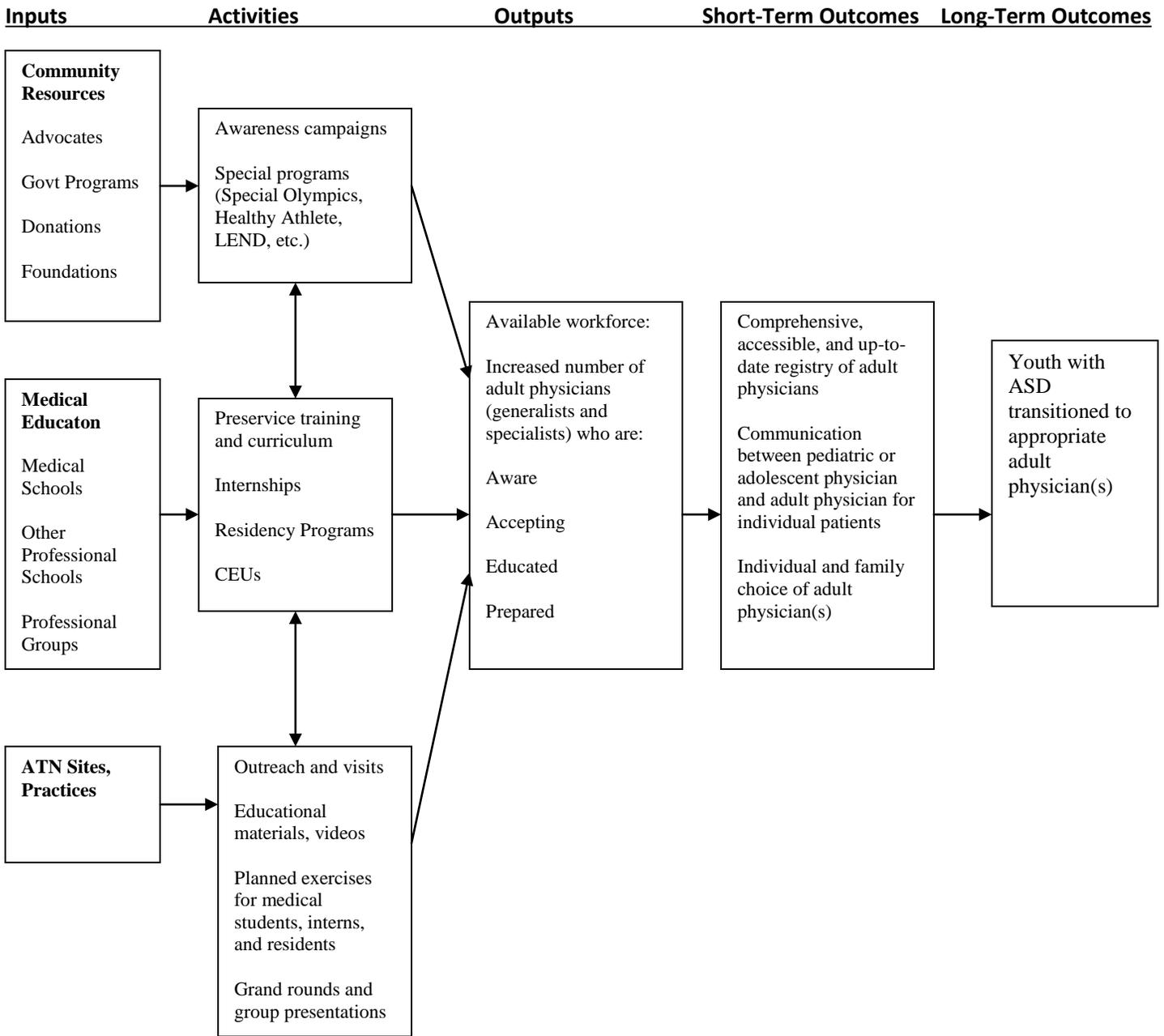
C.) Planned Manuscripts:

1.) We intend to write a paper describing the need for a repository of curricula and other training materials for educating physicians and other health care providers on caring for adults with ASD. We are planning to submit this as a perspectives piece for the Journal of General Internal Medicine.

D.) Other Publications:

1.) Kuhlthau K., Warfield ME, van der Weerd E, Delahaye J, Crossman M. *Autism Transition Resources Guide*. 2012. This is a guide for parents/guardians of youth with ASD who are at or around transition age. It includes 10 online resources designed to support parents and youth through the health care transition process. It was disseminated to all of the sites of the Autism Treatment Network and the Federation for Children with Special Needs. It is also available online through the *MGH Lurie Center's* website and *MassGeneral for Children's* website.

VII.) APPENDIX:



VIII.) References

1. Kuhlthau K, Warfield ME, Crossman M, Delahaye J, van der Weerd E. Transition to adult health care for youth with autism spectrum disorders: Issues and promising new directions. *Society for Research in Child Development Themed Meeting: Transitions from Adolescence to Adulthood*. October 18-20, 2012.
2. Warfield ME, Kuhlthau K, Grossman M, Delahaye J, van der Weerd E. Integrating multiple perspectives on transition to adult health care for youth with ASD: Where do we go from here? *Combating Autism Act Initiative (CAAI)*. May 31, 2013.
3. Bloom SR, Kuhlthau K, Van Gleave J, Knapp AA, Newacheck P, Perrin JM. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012;51(3):213-219.
4. Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *J Adolesc Health*. 2008;43(1):23-29.
5. Reiss J, Gibson R. Health care transition: Destinations unknown. *Pediatrics*. 2002;110(6 Pt 2):1307-1314.
6. McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: Development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *J Child Health Care*. 2006;10(1):22-42.
7. Lotstein DS, Ghandour R, Gash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: Results from the 2005-2006 national survey of children with special health care needs. *Pediatrics*. 2009;123(1):e145-52.
8. Lotstein DS, Kuo AA, Strickland B, Tait F. The transition to adult health care for youth with special health care needs: Do racial and ethnic disparities exist? *Pediatrics*. 2010;128 Suppl 3:S129-36.
9. Reiss J, Gibson RW. At what cost? *Arch Pediatr Adolesc Med*. 2006;160(10):1079-1080.

10. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: Results from the national survey of children with special health care needs. *Pediatrics*. 2005;115(6):1562-1568.
11. Reiss JG, Gibson RW, Walker LR. Health care transition: Youth, family, and provider perspectives. *Pediatrics*. 2005; 115(1):112-120.
12. Callahan ST, Cooper WO. Access to health care for young adults with disabling chronic conditions, *Arch Pediatr Adolesc Med*. 2006;160(2):178-182.
13. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ--transition readiness assessment questionnaire. *J Pediatr Psychol* 2011 ;36(2):160-171.
14. Van Naarden Braun K, Yeamgin-Allsopp M, Lollar D. A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disabil Rehabil*. 2006;28(15):915-928.
15. Salkever DS. Activity status, life satisfaction and perceived productivity for young adults with developmental disabilities. *J Rehabil* 200;66(3):4-13.
16. Macneil BM, Lopes VA, Minnes PM. Anxiety in children and adolescents with Autism Spectrum disorders. *Research in Autism Spectrum Disorders*. 2009;3:1-21.
17. Mayes SD, Calhoun SL, Murray MJ, Ahuja M, Smith LA. Anxiety, depression, and irritability in children with autism relative to other neuropsychiatric disorders and typical development. *Research in Autism Spectrum Disorders*. 2011;5:474-485.
18. . Mayes SD, Calhoun SL, Murray MJ, Zahid J. Variables associated with anxiety and depression in children with autism. *Journal of Developmental and Physical Disabilities*. 2011;23:325-337.
19. . Kanne SM, Abbacchi AM, Constantino JN. Multi-informant ratings of psychiatric symptom severity in children with autism spectrum disorders: The importance of environmental context. *J Autism Dev Disord*. 2009;39(6):856-864.
20. White SW, Oswald D, Ollendick T, Scahill L. Anxiety in children and adolescents with autism spectrum disorders. *Clin Psychol Rev*. 2009;29(3):216-229.
21. Spratt EG, Nicholas JS, Brady KT, et al. Enhanced cortisol response to stress in children with autism. *J Autism Dev Disord*. 2012;42(1):75-81.

22. Corbett BA, Schupp CW, Levine S, Mendoza S. Comparing cortisol, stress, and sensory sensitivity in children with autism. *Autism Res.* 2009;2(1):39-49.
23. Richdale AL, Schreck KA. Sleep problems in autism spectrum disorders: Prevalence, nature, & possible biopsychosocial aetiologies. *Sleep Med Rev.* 2009;12(6):403-411.
24. Cortesi F, Giannotti F, Ivanenko A, Johnson K. Sleep in children with autistic spectrum disorder. *Sleep Med.* 2010;11(7):659-664.
25. Tudor ME, Hoffman CD, Sweeney DP. Children with autism: Sleep problems and symptom severity. *Focus on Autism and Other Developmental Disabilities.* 2012:1-9.
26. Wang LW, Tancredi DJ, Thomas DW. The prevalence of gastrointestinal problems in children across the United States with autism spectrum disorders from families with multiple affected members. *J Dev Behav Pediatr.* 2011;32(5):35-360.
27. Ibrahim SH, Voigt RG, Katusic SK, Weaver AL, Barbaresi WJ. Incidence of gastrointestinal symptoms in children with autism: A population-based study. *Pediatrics.* 2009;124(2):680-686.
28. Jyonouchi H. Autism spectrum disorders and allergy: Observation from a pediatric allergy/immunology clinic. *Expert Rev Clin Immunology.* 2010;6(3):397-411.
29. Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National survey of children's health. *Arch Pediatr Adolesc Med.* 2006;160(8):825-830.
30. Shibata A, Hitomi Y, Kambayashi Y, et al. Epidemiological study on the involvements of environmental factors and allergy in child mental health using the autism screening questionnaire. *Research in Autism Spectrum Disorders.* 2013;7:132-140.
31. Aylott J. Improving access to health and social care for people with autism. *Nurs Stand.* 2010;24(27):47-56; quiz 58.
32. Shea V, Mesibov GB. Adolescents and adults with autism. In: Volkmar FR, Paul R, Klin A, Cohen D, eds. *Handbook of autism and pervasive developmental disorders, vol 1: Diagnosis, development, neurobiology, and behavior.* 3rd ed. Hoboken: Wiley; 2005:288-311.
33. Williams D. *Exposure anxiety –the invisible cage: An exploration of self-protection responses in the autism spectrum and beyond.* London: Jessica Kingsley Publishers: 2003.
34. Cheak-Zamora NC, Yang X, Farmer JE, Clark M. Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics.* 2013;131(3):447-454.
35. Magrab PFL, Millar HEC. Growing up and getting medical care: Youth with special health care needs. A summary of conference proceedings. *Surgeon General's Conference.* 1989.

36. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The national survey of children with special health care needs chartbook 2005-2006. In: Rockville, Maryland: U.S. Department of Health and Human Services; 2008. <http://mchb.hrsa.gov/cshcn05/MI/cokmp.pdf>.
37. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6 Pt 2):1304-1306.
38. Florida Developmental Disabilities Council. Welcome to Health Care Transition Web site. <http://hctransitions.ichp.ufl.edu/ddcouncil/index.php>. Published 2005. Accessed 9/05, 2013.
39. Ritchie J and Spencer L (1994) Qualitative data analysis for applied policy research. In: Bryman A and Burgess R (eds) *Analyzing qualitative data*. London: Routledge; pp 173-194.
40. Smith J and Firth J (2011) Qualitative data analysis: The framework approach. *Nurse Researcher* 18(2):52-62.
41. Lacey A and Luff D (2009) Qualitative data analysis. The NIHR RDS for the East Midlands/Yorkshire & the Humber.
42. Boyatzis RE (1989). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage Publications Inc.
43. Ritchie J and Lewis J (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage Publications Inc.