

**Delaware Transition Initiative:
Alfred I. duPont Hospital for Children
Transition Survey Project**

Phase I Report: Postcard Survey

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Executive Summary

This report explored the experiences of young adults with chronic health conditions and disabilities with the adult health care system after transitioning out of pediatric health care. In particular, the report looked at young adults' access to primary care physicians (PCP) and specialists, and their satisfaction with services they received from PCPs and specialists.

Two thousand surveys were sent out to young adults who had transitioned out of a local children's hospital in the last few years. A total of 263 surveys were returned, and 226 met the criteria for inclusion in the study. Fifty-two percent of the surveys had been completed by the former pediatric patient, and 48% were completed by the former patients' legal guardians.

Findings:

- The majority of former patients has access to a primary care physician
- The majority of young adults has access to (a)specialist(s), while one third reported that they did not have (a) specialist(s)
- A large majority of young adults is very satisfied with their primary care physician while a small number is not satisfied with their PCP
- A majority of young adults is very satisfied with their specialist(s) and a smaller number of former patients is only somewhat or not satisfied with their specialist(s)

The postcard survey provided a first look into young adults' experiences with the adult health care system once they transitioned out of pediatric care. More research is needed to gain a better understanding of the overall transition experience. Additional project activities will provide a more in-depth look into young adults' transition experience.

Section 1: Introduction and Project Overview

Introduction and Project Overview

For the past decade, the family members, physicians, therapists, educators, and service providers who belong to the Delaware Coordinating Council for Children with Disabilities (DCCCD), the state's Children with Special Health Care Needs (CSHCN) office, and the Alfred I. duPont Hospital for Children (AIDHC) Transition Committee have been interested in young adults with chronic conditions and disabilities as they transition from specialized pediatric health care systems into community-based adult health care systems. Because of this interest, the *Delaware Transition Initiative: The Alfred I. duPont Hospital for Children Transition Survey Project* was developed.

The DCCCD is a non-profit agency comprised of governmental and non-governmental agency representatives, the AIDHC, family members, and interested parties across the state of Delaware. The DCCCD mission is to “promote coordinated action among all service providers and organizations, both public and private, concerned with the service needs of children with disabilities in Delaware” (personal conversation with Dr. Bartoshesky, Chair, DCCCD, on December 7, 2006). In 2001, the DCCCD became active as an advisory committee for the state's CSHCN program and has been involved in a variety of projects since. Some of the projects the DCCCD has conducted include:

- a) a review of data for the Maternal and Child Health Block Grant,
- b) a review of the 2001 State and Local Area Integrated Telephone Survey (SLAITS) of CSHCN results,
- c) and a review and adoption of the six CSHCN performance measures as part of Delaware's CSHCN State Plan.

Throughout these projects, the DCCCD has maintained a focus on the issue of transition services for youth with special health care needs from specialized pediatric health care to community-based adult health care and support.

Expressed Need

The Alfred I. duPont Hospital for Children (AIDHC), a division of Nemours, is the largest health care provider for children with disabilities in Delaware and operates one of the nation's largest subspecialty group practices devoted to pediatric health care. In 2002, over 500 young adults being treated at AIDHC for chronic illnesses, disabilities, or diseases aged out of services and needed to transition to community-based adult health care.

The AIDHC Transition Committee has expressed interest and concern about the transition experiences of young adult patients as they move to the adult health care system. The transition committee has also expressed interest in what AIDHC staff could do to support the transition, both for the young adults leaving AIDHC services and for the community providers who will be supporting their health care needs. Based on their experiences, the AIDHC Transition Committee and DCCCD members perceived the transition from pediatric to adult care as difficult for many young adults and their families. The AIDHC Transition Survey Project was

designed to gather information about the transition from AIDHC to community-based health care services and explore the experiences of former AIDHC patients who have made this transition.

Research Questions

To address the interests of the transition committee and the DCCCD, three research questions were posed to address the following issues:

1. Do young adults who leave pediatric medical care at AIDHC have primary and specialized adult medical care to address their typical and specialized chronic health care needs?
2. To what type of adult health care services do young adults have access after they transition from AIDHC?
3. How satisfied are these young adults and their families with the care they receive in the community-based adult health care system?

Project Goals

The transition survey project had two goals. The first goal of the project was to develop strategies that helped demonstrate Delaware's progress on the six national aims for CSHCN.

The six CSHCN aims are part of the *President's New Freedom Initiative*, which is dedicated to the elimination of barriers that prevent people with disabilities from full community inclusion.

The six aims for CSHCN are:

- a) family inclusion in decision making,
- b) coordinated services within a medical home model,
- c) adequate insurance coverage,
- d) early and continuous screenings for special health care needs,

- e) services that are organized in an easy-to-use manner,
- f) and the assurance that all youth with special health care needs receive the support they need to successfully transition into adulthood.

The second goal was to investigate the transition experiences of young adults and based on the findings, provide recommendations on how to support youth and help to ensure successful transitions.

Timeline

This project was conducted in three phases. Phase I included the collection and analysis of data about access to primary care physicians and specialists and satisfaction with these services. This phase used a short postcard survey that was sent out to 2,000 former patients of AIDHC. Phase II will include the collection and analysis of data from a detailed survey on the transition experiences of approximately 150 former patients. Phase III will include data collection and interpretation from family focus group sessions on transition issues. However, this report is only based on the data collected for Phase I of the project.

Section 2: Background Information and Literature Review

National Trends

Nationwide, there are approximately 9.3 million children and youth, or 12.8% of all children between birth and 17 years of age in the United States, who have special health care needs (Child and Adolescent Health Measurement Initiative, 2005). Of this group, 60.0% are male, and 40.0% are female. Children and youth with special health care needs (CYSHCN) are often divided into three age groups with 40.8% from 12 to 17 years of age, 39.7% from six to 11 years of age, and 19.5% from birth to five years of age. Based on this information, approximately 3.8 million youth with special health care needs, their families, and health care providers across the country need to be prepared for the transition of these youth to adult community-based health care services.

In addition to the large number of youth who need transition services, the expanding longevity of this group is also an issue. Early detection of special health care needs, advances in medical interventions, and more effective health service systems have resulted in children with chronic conditions living well into adulthood (Lotstein, McPherson, Strickland, & Newacheck, 2005). This increased longevity calls for a need to have a smooth, well-coordinated, effective transition from specialized pediatric health care services to community-based adult health care services.

Findings of the National Survey of Children with Special Health Care Needs (NS-CSHCN) point out that adequate preparation for transition from pediatric to adult health care services is lacking. The NS-CSHCN is a survey that is conducted by the National Center for Health Statistics (NCHS) for the Maternal and Child Health Bureau to estimate the prevalence of CYSHCN across all states and to assess children's health care needs and their use of health care services. The survey uses random-digit dialing to generate a sample and the State and Local Area Integrated Telephone Survey (SLAITS) collects information from parents of children and youth with special health care needs between birth and 17 years. Between October 2000 and April 2003, a total of 38,866 parents of CYSHCN participated in the most recent survey. Of the 38,866 guardians, 13,885 are guardians of youth 13 to 17 years. Of the 13,885 guardians of youth 13 to 17 years included in the survey, 5,533 were asked about transition issues.

Fifty percent of guardians of youth 13 to 17 years of age who responded to the SLAITS reported that their doctors talked with their family about how the health care services of adolescents with special health care needs might change as they become adults. However, only 5.8% of the respondents felt that their children received the health care services necessary for a successful transition (Child and Adolescent Health Measurement Initiative, 2005). Further, respondents reported that only 20.7% of doctors and other pediatric health care providers discussed the transition process with adult health care providers. In addition, only 29.1% of the respondents reported that their doctors and other health care providers developed a plan for their children's changing health care needs (Child and Adolescent Health Measurement Initiative, 2005).

In a study focusing on adolescent health care transition, Reiss, Gibson, and Walker (2005) conducted 34 focus groups with a total of 143 participants. This study included the

perspectives of 49 youth and young adults, 44 family members, and 50 providers. Reiss et al identified four factors that have a major impact on the transition process:

- a) a transition being approached as a developmental process that needs to start in childhood,
- b) the differences between the pediatric and adult system,
- c) finances,
- d) and the reciprocal relationships of providers, family members, and CYSHCN.

In a larger study, Scal and Ireland (2005) used data from parents of 4,332 adolescents who participated in the NS-CSHCN between 2000 and 2001 and found that those adolescents who were older and had more complicated medical needs were more likely to have transition planning than youth who had less complicated medical needs. They also found that there was a strong association between high-quality relationships between parents and health care providers and preparation for transition.

All of these national studies illustrate the need for purposefully, planned, systematic transition preparation for youth moving from a pediatric health care system to an adult health care system.

Delaware Data

In Delaware, the approximate number of CYSHCN is 30,409, or 15.3% of all children from birth to 17 years of age (Child and Adolescent Health Measurement Initiative, 2005). This is slightly higher than the national average of 12.8%. (Child and Adolescent Health

Measurement Initiative, 2005). Of these children and youth in Delaware, 60.7% are male, and 39.3% are female. By age, Delaware's CYSHCN are very similar to the national trends. Youth aged 12 to 17 years account for 39.7% of CYSHCN in Delaware. Just over 40% of CYSHCN in Delaware are from six to 11 years of age, and 19.6% are between the ages of birth and five years. According to data from the NS-CSHCN, only 7.0% of all children and youth with special health care needs age 13 to 17 in Delaware received the services necessary to make a successful transition into adult health care services.

Nationally, as well as in Delaware, specific findings regarding the transition of CYSHCN from pediatric into adult health care settings demonstrate a lack of appropriate transition preparation and the absence of services needed to make a successful transition. These findings indicate the need for more in-depth knowledge about young adults' transition experiences and more specific recommendations about how to improve the transition process so that the sixth CSHCN aim, "all youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence," of the *President's New Freedom Initiative* can be achieved. Phase I of this project was a first step in providing information about the transition experiences of CYSHCN in Delaware.

Section 3: Method

Data for this project was collected via a five-question survey. The survey addressed the first and third research questions: “Do young adults who leave pediatric medical care at Alfred I. duPont Hospital for Children have primary and specialized adult medical care to address their typical and specialized chronic health care needs?” and “How satisfied are these young adults and their families with the care they receive in the community-based adult health care system?”

Specific survey questions asked former patients or their legal guardians if they currently had a primary care physician; if they were seeing one or more specialists; how satisfied they were with the doctors they were seeing; and if they were interested in further participation in this study. Participants interested in participating in the other two phases of this project had the option to provide their name and telephone number and could indicate what their chronic condition was and how long it had been since they transitioned from services provided by Alfred I. duPont Hospital for Children (AIDHC).

The survey was mailed to 2,000 randomly selected former patients of AIDHC who had chronic conditions and disabilities and who had transitioned from AIDHC within the last five years. However, as shown in the findings section of this report, some participants indicated that they transitioned from AIDHC services five or more years ago.

Addresses for the 2,000 randomly selected former patients were compiled by the AIDHC data warehouse, and the business development office mailed the surveys. The mailing included a cover letter explaining the purpose of the project, the survey, and a business-reply envelope. The cover letter indicated that the survey was available in Spanish and that these Spanish surveys could be requested by calling the project coordinator. Return envelopes were addressed to AIDHC to protect the personal information of patients. Returned surveys were coded by the principal investigator (PI) and the project coordinator, and the coded data were entered into a Statistical Package for the Social Sciences (SPSS) database. No identifying information was entered into the SPSS database.

Former patients or their legal guardians indicated on the survey if they were interested in participating further in this study. If so, they provided their names and telephone numbers in an allocated space on the survey. Their names and phone numbers were entered into a coded spreadsheet that will be used to contact potential participants for the second and third phases of the project. To protect participants' identifiable information, the spreadsheet is kept on a password-protected computer in the PI's office at AIDHC. Further, all returned surveys are kept in a locked filing cabinet in the PI's office at AIDHC and will be destroyed after two years.

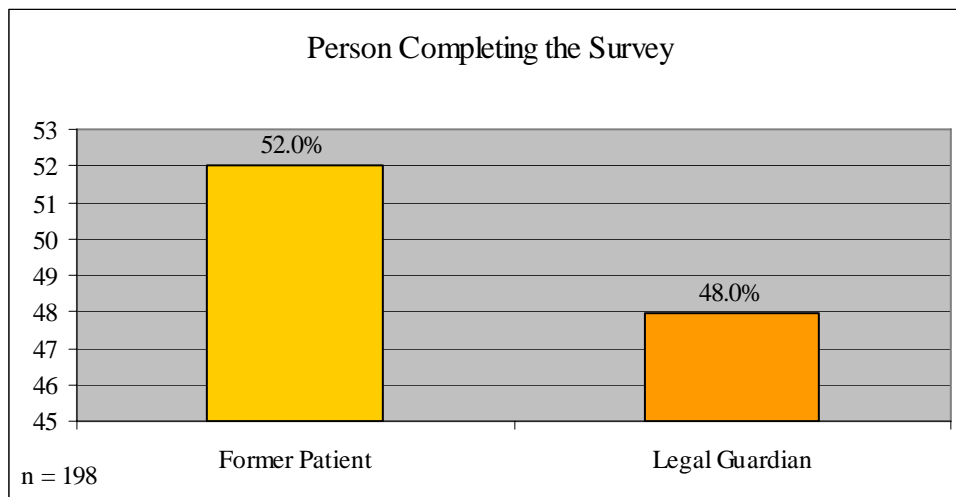
Two-thousand surveys were distributed in November of 2006. A total of 263 surveys were returned (13.2% return rate). Of these 263 respondents, 164 indicated that they were interested in participating further in this project (72.6%). A total of 226 of the 263 returned surveys met the criteria for participation and were included in the data analysis. The following section is an analysis of the data by each question.

Section 4: Findings

Demographic Information

In this postcard survey, questions asked who completed the survey (former patient or legal guardian); what the former patients' illness, chronic condition, or disability was; and how much time had past since the patient had stopped receiving services from the Alfred I. duPont Hospital for Children (AIDHC). While providing this information was voluntary, the vast majority of respondents chose to complete this section of the survey. Of the respondents who answered this question, 52% were former patients, and 48% were the legal guardians of former patients (see Figure 4.1. for details).

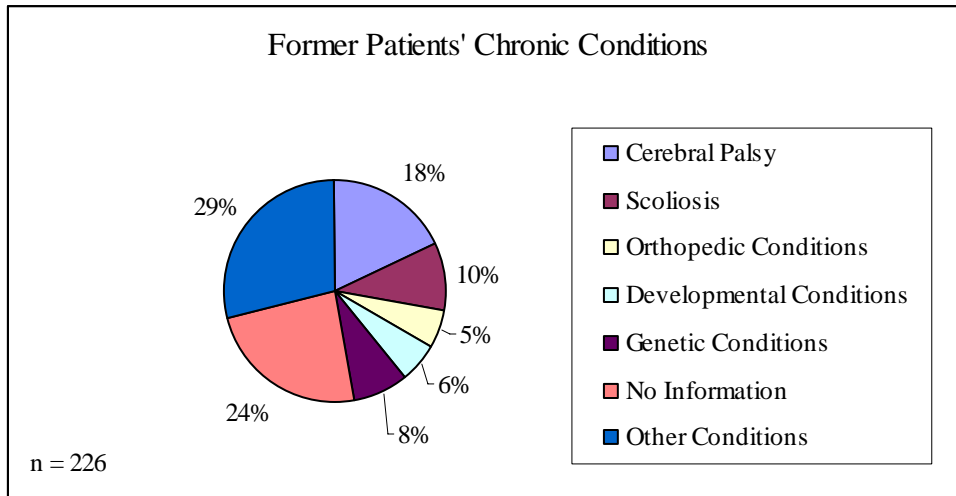
Figure 4.1. Person Who Completed the Survey



Respondents were asked about their illnesses, chronic conditions, and disabilities, completing the question by writing their condition into a blank space on the survey. Participants identified almost 40 different conditions.

Of the 226 respondents, 18% indicated that their chronic condition was cerebral palsy. Another 10% reported their chronic condition as scoliosis. Almost 25% of the respondents did not indicate a chronic condition, and 29% of the respondents had conditions that were categorized as “other conditions” (see Figure 4.2. for details). These included conditions such as biliary atresia, leukemia, Crohn’s disease, traumatic brain injury, asthma, and juvenile rheumatoid arthritis. (For a detailed list of conditions that were categorized as “other conditions,” see Appendix A.)

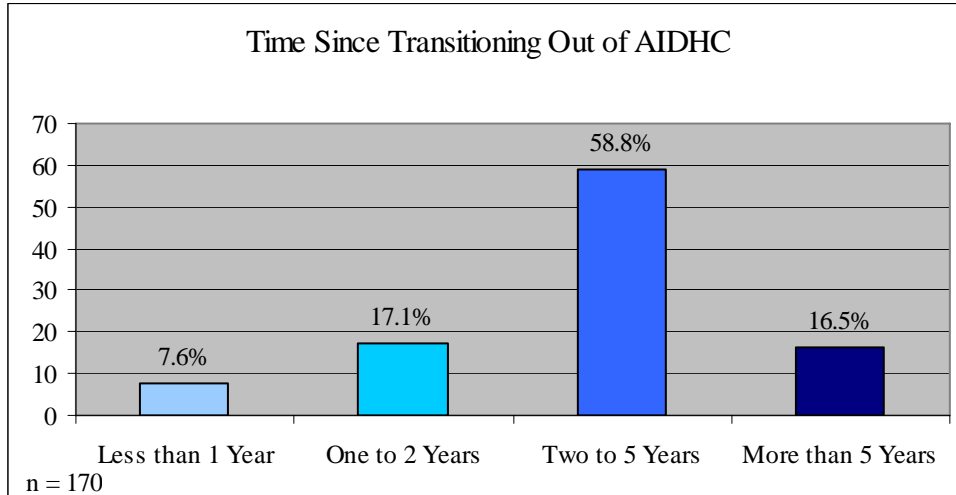
Figure 4.2. Illness, Chronic Condition, or Disability of Participant



Respondents were also asked how long it had been since they had transitioned from AIDHC services to community-based adult health care. More than half of all participants who answered this question (58.8%) reported that they had left services two to five years ago. Over 17% of the respondents had transitioned one to two years ago, 16.5% had transitioned five or

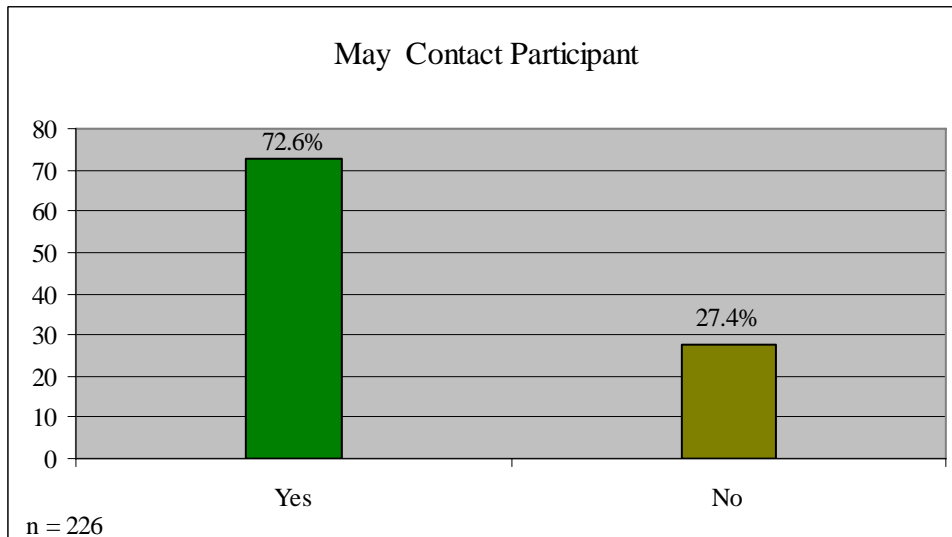
more years ago, and 7.6% reported that they transitioned less than a year ago (see Figure 4.3. for details).

Figure 4.3. Time Since Transitioning Out Of Alfred I. duPont Hospital for Children



A large majority (72.6%) of respondents indicated that they wanted to participate in future activities of the project, which is shown in Figure 4.4.

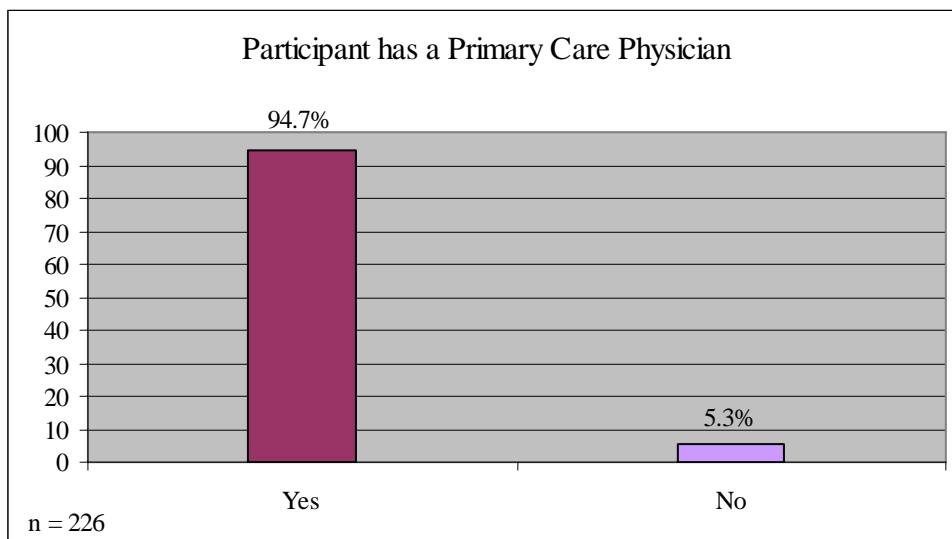
Figure 4.4. Continued Participation in Project



Having a Primary Care Physician

The vast majority of respondents (214) reported that they had a primary care physician (PCP), and only 12 participants indicated that they did not have a PCP. Figure 4.5. illustrates the percentages of respondents indicating that they had a PCP versus the respondents who do not have a PCP.

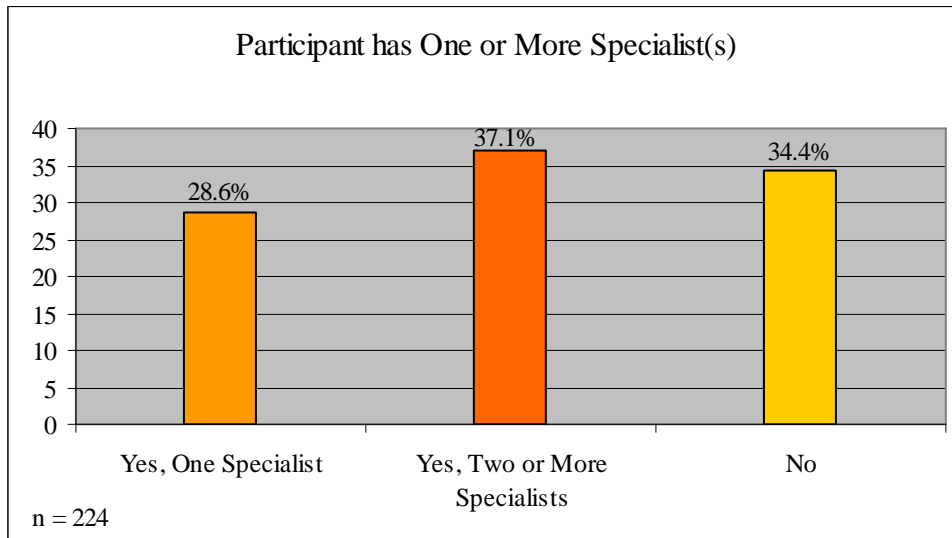
Figure 4.5. Having a Primary Care Physician



Having One or More Specialists

A total of 65.7% of the respondents indicated that they had access to a health care specialist. Over 37% reported they had more than one health care specialist. Over a third of the respondents indicated that they did not use or have access to a health care specialist (see Figure 4.6. for details).

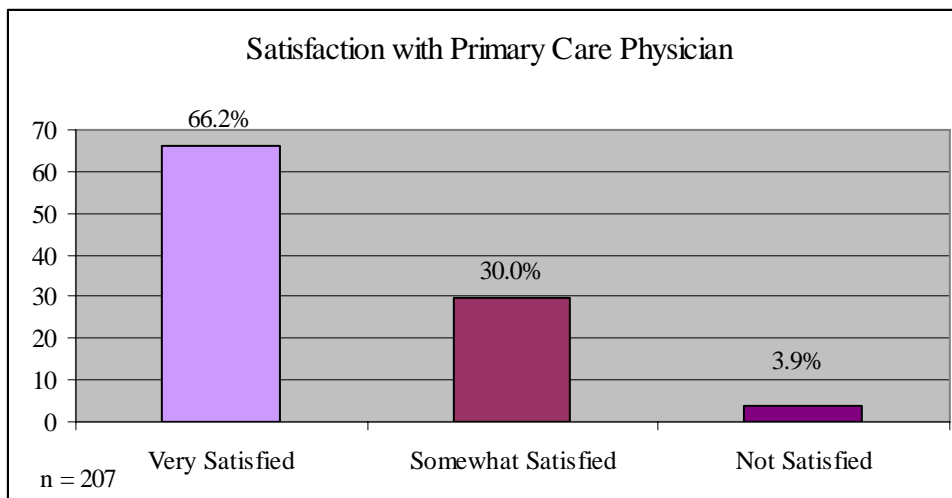
Figure 4.6. Having One or More Specialists



Satisfaction with a Primary Care Physician

The large majority of participants stated that they were very satisfied (66.2%) with their primary care physician (PCP). However, 30% of participants were only somewhat satisfied, and 3.7% of respondents were not satisfied with their PCP.

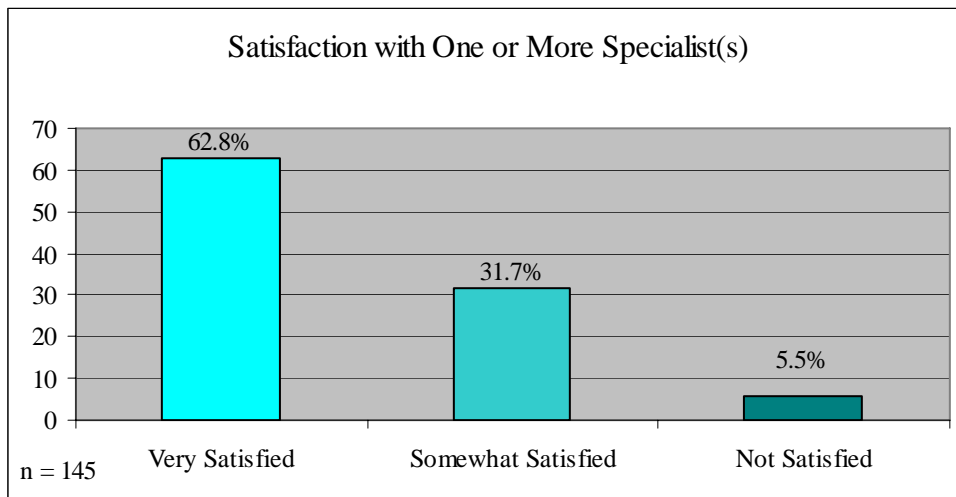
Figure 4.7. Satisfaction with a Primary Care Physician



Satisfaction with One or More Specialist(s)

Of all participants indicating that they had one or more specialists, 62.8% reported that they were very satisfied with their health care specialist(s). Over 31% of respondents were only somewhat satisfied with their specialist, and 5.5% of respondents indicated that they were not satisfied with their specialist (see Figure 4.8. for details). For a large number of participants (35.8%), this question was not applicable because they had indicated that they did not use a health care specialist.

Figure 4.8. Satisfaction with One or More Specialist(s)



Unsolicited Qualitative Comments

Though this survey was designed as a closed-ended questions survey, 13 (5.7%) participants provided qualitative information about their transition experiences. Table 4.1. reports and categorizes the written comments that respondents provided. Comments were divided into four categories: a) not finding the right physician, b) disability as an obstacle to transition, c) satisfaction with the pediatric services, and d) other.

Table 4.1. Qualitative Comments About Transition Experiences

Not Finding the Right Physician	Disability as an Obstacle to Transition	Satisfaction with Pediatric Services	Other
<p>“If you can help us find a primary care physician who specializes in head injury in young adults it would be a big help for us because I don't know who to turn to.”</p>	<p>“There has been a problem locating an orthopedic specialist who will accept a severely disabled adult.”</p>	<p>“We were very happy with duPont and we only transferred because of [our son's] age.”</p>	<p>“I have not been able to afford medial care since I was released from A. I. duPont.”</p>
<p>“We can't find a substitute for Dr. J. in this area.”</p>	<p>“It is not an easy transition when the child is severely disabled. All of the specialists were at duPont; now it is up to the parents to find the specialists they need, and they are not centralized.”</p>	<p>“No one can compare to Dr. R. and Dr. A.”</p>	<p>“We would like to help future parents transition.”</p>
		<p>“My daughter was a patient from 1985-2001. We miss the medical care she received there and would be very interested to resume care there.”</p>	<p>“We took care of all of [our son's] major issues before he became too old for A. I.”</p>
		<p>“AIDHC should consider a program of specialized care for former pediatric patients. [Our daughter] had spinal fusion...at age 17. We are concerned that it will be difficult to obtain top quality care if [our daughter] has complications... as an adult.”</p>	<p>“Transition is very difficult. We appreciate all the help that the duPont physicians are able to give us but the absolute cut-off is very disturbing as there are often conditions being treated that happen at a difficult time - mid treatment. The doctors should be able to treat if the cut -off time falls during treatment.”</p>
			<p>“Hopefully transition services have begun for current patients.”</p>

Section 5: Conclusions and Next Steps

Information from this survey provides a first glance into former Alfred I. duPont Hospital for Children (AIDHC) patients' experiences with transition from a specialized pediatric health care system to community-based adult health care systems. Findings indicate that the majority of respondents have access to a primary care provider as well as health care specialists. Overall, respondents report being satisfied with the health care they receive from their physicians and specialists in the adult health care system. However, a number of respondents were only somewhat satisfied or not satisfied with their primary care physicians and specialists. It is not known what the reasons for their dissatisfaction are, and follow-up research is needed to determine participants' reasons for dissatisfaction. A large number of respondents also indicated that they did not have a health care specialist. This may be due to respondents' non-necessity for specialized health care. However, it could also be due to an inability to find specialized care providers. Future investigations are needed to determine if respondents without specialists need those services yet have not been able to secure them.

The unsolicited written responses on the surveys provided some information about why former pediatric patients and their families perceive transition as a difficult process. The comments indicated that families find it difficult to identify appropriate medical care for young adults in the community-based adult health care systems. The comments also indicated that adult health care does not compare favorably to the care that had been received in the pediatric

setting. More research is needed to gain a better understanding of the respondents' perceptions regarding the transition process.

The survey for Phase I had some limitations to consider when examining the findings. The response rate is small but typical of mail surveys. Single-mailed surveys usually result in response rates of 9-12%. For this survey, just over 13% of those who received the mailed surveys responded. It is possible that the respondents do not represent the larger group of all youth who have transitioned into community-based adult health care services. However, despite the relatively small response rate, the profile of respondents was very similar to children and youth with special health care needs nationwide.

Another limitation is that no Spanish-speaking families responded to the survey. While the surveys stated in Spanish that families could request a Spanish version, neither the principal investigator nor the project coordinator was contacted for a Spanish copy of the survey.

The Delaware Transition Initiative: The Alfred I. duPont Hospital for Children Transition Survey Project has two additional phases planned. Phase II will further explore transition topics, such as access and utilization of care in the community-based adult care systems; collaboration between patients and doctors; and collaboration between pediatric and adult physicians. Through focus group sessions with families, Phase III of the project will provide insight into respondents' experiences with transition. In addition, families will have the opportunity to provide recommendations for the improvement of the transition process from pediatric health care to adult health care.

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Appendix

Appendix: Chronic Conditions Classified as “Other Conditions”

Condition	Number of participants who indicated that they had this condition, in descending order of frequency.
Spina Bifida	7
Asthma/Allergies	5
Crohn’s Disease	5
Diabetes	5
Juvenile Rheumatoid Arthritis	4
Charcot Marie Tooth Disease	3
Traumatic Brain Injury	3
Biliary Atresia	2
Lupus	2
Seizures/Epilepsy	2
Anoxic brain damage due to near drowning	1
Brain Tumor	1
Cerebral Vascular Accident	1
Cystic Fibrosis	1
Deaf in right ear	1
Depression	1
Fetal Alcohol Syndrome	1
Hodgkin Disease	1
Hydrocephalus	1
Hypothyroidism	1
Large Granula Lymphocytic Leukemia	1
Migraine	1
Morphea	1
Multiple Disabilities	1
Myotonic Dystrophy	1
Neurocardiogenic Syncope	1
Neurofibromatosis	1
Obesity	1
Osteogenesis Imperfecta	1
Rhenoid Disease	1
Sickle Cell Anemia	1
Spinal Cord Injury	1
Stickler Syndrome	1
Still have not gotten diagnosis	1
Tourette Syndrome	1
Von Wellabrand’s Disease	1
Diagnosis not legible	1
Total number in category “Other Conditions”	65

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