

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

**Final Report**

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## EXECUTIVE SUMMARY

This report explores 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 focuses on young adults' access to primary care physicians (PCP) and specialists, comparison of the pediatric and adult systems, satisfaction with services, and recommendations on how to improve the overall transition process. Data for this report were collected in three phases: a) Phase I, the postcard survey, b) Phase II, the extended survey, and c) Phase III, the focus group sessions. Findings of this report should be interpreted with caution since sample sizes from the conducted surveys were small.

Three main research questions guided this project:

1. 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?
2. To what types 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?

Findings from the extended survey regarding these guiding questions showed that 1) most young adults who participated in this survey have a primary care provider and a smaller number of participants also have one or more specialist(s), though one third do not have a specialist. Reasons for not having a primary care provider or specialist(s) include a) not knowing of the appropriate physician and b) challenges with transportation to physicians. In answering the second question of this project, participants reported that 2) they have access to a) general medical services, b) therapeutic services, c) mental health services, d) private duty home health care, and e) community rehabilitation and day programs. However, only 64% reported that mental health and private duty home health care are available to them, and only 46.8% reported that community rehabilitation and day programs are available in their communities. Regarding the third research question, the majority of respondents were overall satisfied with their primary care providers and specialists; however almost a quarter or respondents were very dissatisfied or dissatisfied with their primary care physician, and almost 10% were very dissatisfied or satisfied with their specialist(s).

In Phase I, the postcard survey, two thousand postcard 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. Findings from the postcard survey revealed that:

- The majority of former patients have access to a primary care physician.

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

In phase II, the extended survey, surveys were sent to participants who indicated on their postcard survey that they were interested in further participation in this study. A total of 155 participants provided the Center for Disabilities Studies with their contact information (email or telephone). Out of these 155, the research team was able to contact 95. A total of 49 surveys were completed and returned. Findings from the extended survey showed that:

- Respondents were equally divided between finding the transition process from pediatric to adult health care easy or difficult.
- Half of all respondents preferred the pediatric health care system over the adult health care system.
- Half of survey respondents thought that pediatric and adult health care insurance coverage were equally good.
- Most survey respondents reported that they have an adult primary care provider (PCP).
- Half of all former pediatric patients reported that they do not have a specialist; of those, 39% reported that they do not have a specialist because they do not know the type of specialist(s) that they need.
- Overall, former pediatric patients were satisfied with their adult PCPs and specialists; however, almost a quarter of survey respondents were dissatisfied with their current PCP and almost 10% were dissatisfied with their current specialist.
- Most survey participants have access to general medical services in their communities; however, mental health services and private duty home health care are available to only 64% of respondents, and community rehabilitation and day programs are available to only 47% of all participants.

Finally, in Phase III, the focus group sessions, two focus groups were conducted with former pediatric patients and parents who were interested in participating in these sessions in addition to completing the extended survey. Seven individuals participated; three were former patients and four were parents. The focus group sessions addressed difficulties experienced in the transition process and recommendations for how the process could be improved. Areas that were difficult included:

- The sometimes abrupt discontinuation of pediatric services once a patient was considered to be an adult (18-21 years of age).
- Identifying adult primary care providers (PCPs) and specialists.

- Receiving the same amount of care from adult physicians that pediatric physicians had provided.
- Reduced health insurance coverage.

Five recommendations were provided by focus group participants. These recommendations primarily revolve around coordination of the transition process, communication between pediatric and adult physicians and physicians and parents, and insurance coverage. The recommendations are as follows:

- Establish a transition team that provides transition preparation services to young adults and their families throughout the transition process.
- Provide transition resources to young adults and their families, including a list of adult primary care providers and specialists that will accept patients with difficult medical conditions and multiple disabilities and a discharge summary form that outlines a patient's diagnosis, medical history, medications, and needs.
- Improve collaboration and communication among pediatric physicians, parents, and adult physicians to improve medical treatment of the young adult.
- Take a long-term care approach to insurance coverage so money can be saved in the long run while needed services and equipment are covered immediately for young adults.
- Conduct more research on pediatric conditions in adult patients so treatment of these patients can be improved.

Overall, this pilot project showed that while a majority of respondents are satisfied overall with the adult health care they receive, more specific transition services are needed to improve the overall transition experience of young adult patients and their families. **Based on all three phases of this pilot project, the following recommendations are provided for the improvement of the transition process from the pediatric to the adult health care system:**

- 1. Conduct another survey about the transition process with a larger, more diverse sample.** More information from a larger, more diverse sample is needed to be able to make some statements about the transition process that can be generalized to the whole population of young adults and their families who transition from the pediatric to the adult health care setting. This survey could be conducted by the Alfred I. duPont Hospital for Children (AIDHC) or state agencies, such as the Office of Children with Special Health Care Needs of the Delaware Division of Public Health.
- 2. Explore existing adult community services for individuals with medical conditions and disabilities for gaps in service delivery.** From this pilot project it is not apparent if described gaps in community services exist or if survey participants lacked the knowledge that these services are available in their communities. Therefore, more information about the availability of community services is needed. Such an evaluation could be conducted by the Office of

Children with Special Health Care Needs of the Delaware Division of Public Health.

- 3. Educate adult health care providers on the needs of transitioning youth and their families.** Adult health care providers should receive information about young adults' experiences in the pediatric setting, their needs and their expectations. This could be done through interactive media or lecture-style presentations as part of other learning opportunities for medical professionals.
- 4. Begin the process of exploring collaborative efforts between pediatric and adult physicians.** The Alfred I. duPont Hospital for Children (AIDHC) Transition Committee should begin the process of talking to adult services colleagues from hospitals, rehabilitation facilities, and regional primary care providers and specialists about collaborative efforts in supporting patients in their transition from pediatric to adult health care. Pediatric and adult physicians could explore existing collaboration models and develop and implement a plan for improved communication.
- 5. Begin the process of exploring ways to provide needed transition resources to families and patients who are in the transition process.** The AIDHC Transition Committee should collaborate with existing state and community organizations and other surrounding states' organizations on developing and disseminating information brochures and websites that address transition topics. Existing resources could be identified, modified, and publicized so young adults in transition have access to and know where to find useful transition information.
- 6. Begin exploring the development of a transition coordination team that assists families and patients in their transition from the pediatric to the adult health care setting.** The AIDHC Transition Committee should address the need for a formalized transition process and develop a plan for such a process. This includes identifying the target population, how to implement this process, and how to finance this formalized process. Collaboration with other state and community organizations would be helpful in planning for such a process.
- 7. Work to address existing health insurance coverage shortcomings and seek a dialogue with health insurance providers.** The AIDHC Transition Committee and other collaborators should seek the dialogue with insurance providers on how to improve coverage of needed treatments, therapies, and equipment.

## **SECTION 1: INTRODUCTION AND 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 Office of Children with Special Health Care Needs (CSHCN) of Delaware's Division of Public Health, 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 since been involved in a variety of other projects. Some of the projects the DCCCD has conducted include: a) review of data for the Maternal and Child Health Block Grant, b) a review of results of the 2001 State and Local Area Integrated Telephone Survey (SLAITS) of CSHCN, and c) a review and adoption of the six CSHCN performance measures to create a system of care for children and their families 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 expressed interest and concern about the transition experiences of young adult patients as they move to the adult health care system. The transition committee 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 would 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 types 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 was to develop strategies that helped demonstrate Delaware's progress on the six national performance measures for CSHCN. The six CSHCN performance measures 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 performance measures 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 transition into adulthood successfully.

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 Alfred I. duPont Hospital for Children (AIDHC). Data was collected between November and December 2006. A report about the findings from Phase I was written and disseminated in December 2006.

Phase II included the collection and analysis of data from a detailed survey on the transition experiences of former patients or their parents/legal guardian who had indicated in the postcard survey that they were interested in participating in the extended survey. Of the 155 individuals who indicated that they were interested in participating in the extended survey, 95 could be contacted. A total of 49 individuals returned the extended survey. Extended survey data were collected between January and April 2007.

The final Phase III consisted of two focus group sessions with former patients and parents on transition challenges and recommendations for improvement of the transition process. Both focus groups were conducted in April 2007. A total of seven individuals participated, four in the first focus group session and three in the second focus group session. Three of the participants were former patients and four participants were parents.

The final report that includes findings from all three phases was completed in May 2007. The report was distributed to relevant state and community organizations and the Alfred I. duPont Hospital for Children in June 2007.

## SECTION 2: BACKGROUND INFORMATION

### National Trends

Nationwide, there are approximately 9.3 million children and youth (12.8%) between birth and 17 years of age 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% aged 12 to 17 years, 39.7% aged six to 11 years, and 19.5% birth to five years. 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 increasing 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 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/guardians of CYSHCN participated in the most recent survey. Of the 38,866 parents/guardians, 13,885 (35.7%) care for youth age 13 to 17 years. Of this latter group, 5,533 (39.9%) were asked about transition issues.

Fifty percent of parents/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, and d) 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.

There are some smaller scale studies with young adults who have a specific medical condition (e.g. Busse, Galler, Stumvoll, Wiessner, Kiess, & Kapellen, 2007; McCurdy, DiCenso, Boblin, et al., 2006) that investigated challenges with the transition process. These studies found that young adults need to be better prepared for the transition into the adult health care system, need a smooth (not abrupt) transition process, and need to receive adequate information and recommendations for future health care providers. Other studies (e.g. Foster & Holmes, 2007; Knauth, Verstappen, Reiss, & Webb, 2006; Por, Golberg, Lennox, Burr, Barrow, & Dennard, 2004) describe the process that is put in place or should be put in place at various health care facilities to improve the transition process. Recommendations include transition specialist teams that help with the transition process, integration of the family in the process, and a close relationship between pediatric and adult clinical staff.

All of these 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 performance measure, "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. Phases II and III provided more in-depth knowledge about challenges and barriers and recommendations on how to reduce or eliminate some of the difficulties families face when their children transition into the adult health care system.

## SECTION 3: METHOD

### Procedures

Data for this project were collected in three phases. The first phase was a five-question postcard survey, the second phase was an extended mail survey, and the third phase involved focus group sessions with former patients and parents/legal guardians of former Alfred I. duPont Hospital for Children (AIDHC) patients. Internal Review Board approval for this pilot project was granted by the Alfred I duPont Hospital for Children in October of 2006.

**The first phase, the postcard survey**, addressed the first and third research questions of this project: “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 have a primary care physician; if they are seeing one or more specialists; how satisfied they are with the doctors they are seeing; and if they are interested in participating further 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 postcard 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 postcard 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 14.0) database. No identifying information was entered into the SPSS database.

Former patients or their legal guardians could indicate 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. This contact information was entered into a coded spreadsheet that was 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.

Of the two-thousand surveys that were distributed in November of 2006, a total of 263 surveys were completed and 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 were completed and were included in the data analysis. Thirty-seven of the 263 returned surveys could not be used since they were not completed or survey participants indicated that they were not interested in participating in the study. The fourth section of this report provides findings from the analysis of the data.

**In Phase II of this project**, the project coordinator and research assistant contacted individuals who had indicated in the postcard survey that they were interested in participating in the extended survey. A standardized phone contact sheet was used when calling or emailing participants. Phone calls were made by the project coordinator and a research assistant from the Center of Disabilities Studies at the University of Delaware between January and April 2007. Out of the 164 respondents who had indicated that they were interested in participating in the extended mail survey, 155 provided the research team with useable names and telephone numbers or email information. Six contacted participants indicated that they no longer wanted to participate and a total of 54 individuals could not be contacted due to disconnected phones, full answering machines or simply because they did not answer their phone. People who could not be reached with the first phone call received two more phone calls on different dates and times and phone messages were left asking for a return phone call

The project coordinator and research assistant were able to contact a total of 95 individuals who received the extended mail survey, a cover letter explaining the purpose of the study, and a business-reply envelope addressed to the Center for Disabilities Studies (CDS). Extended surveys were coded matching the codes of the postcard survey before being sent to participants. This allowed the researchers to keep track of participants who returned the extended survey without having to use identifying information.

A total of 49 individuals returned the extended survey (51.6%). Due to time and financial limitations, participants who received an extended survey but did not return it were not contacted for follow-up. Returned surveys are secured in a locked drawer in the office of the project coordinator. The surveys will be kept for the next two years and destroyed after that time period.

The extended survey consisted of 64 questions, organized into five sections: a) physicians, b) specialists, c) insurance, d) move to adult health care, and e) background information. Sections in the extended survey addressed all three research questions of this project, including questions about access to primary and specialized health care, access to adult health care services, such as mental health and rehabilitative services, and satisfaction with services. In addition, comparison questions about the pediatric and adult health care system were asked, as well as questions about current and pediatric insurance coverage.

Responses from the returned extended surveys were entered into a statistical database (SPSS 14.0). Since extended surveys only had a code but no other identifying information, no identifying information was entered into the SPSS database. Simple statistical analyses, such as frequencies and descriptives, were run to analyze the data, and figures and tables were used to illustrate the findings. Findings from the extended survey can be found in section five of this report.

**In Phase III, two focus groups** with former patients and parents were held. Focus groups were used to gather more detailed accounts of individuals' personal experiences with transition and to ask participants for recommendations on how to improve the transition process. The original plan was to recruit focus group participants by (a) geographic location; (b) age; (c) disability; and (d) time since transitioning from pediatric to adult health care. However, once the project coordinator and research assistant started calling people who were interested in participating in the extended survey (Phase II), it became apparent that this approach was not feasible. Most participants who were willing to participate in the extended mail survey stated that, while they were generally interested in participating in a focus group, time constraints or distance would not allow them to do so. The researchers then decided to ask every person who was interested in completing the extended survey if they were also interested and willing to participate in a focus group session. Three different dates and times were offered for focus group sessions. A total of 15 individuals signed up for a total of two focus groups. Originally, three focus group sessions had been planned. However, due to the tight timeline of the project and the challenge of finding enough focus group participants, it was not possible to hold a third focus group.

The first focus group was held in early April 2007 in the evening at the Center for Disabilities Studies (CDS), and the second focus group was held in late April 2007 in the evening at CDS. Both focus groups lasted two hours. For the first focus group, seven individuals signed up and four people attended. Three of these individuals were former patients and one was a parent. The individuals who had signed up for the first focus group but did not attend were also invited to attend the second focus group. They received a phone call from the project coordinator (in all three cases the phone was not answered; therefore, the project coordinator left a message re-inviting individuals to the next focus group) and a letter was sent re-inviting them to attend the second focus group. None of these individuals attended the second focus group.

A total of seven individuals signed up for the second focus group and three attended. Four individuals told the researcher the day before, when called with a reminder of the meeting that they were unable to attend the focus group session. The three who did attend were parents of former patients.

All potential focus group attendees received a letter inviting them to the focus group session and explaining what types of questions would be asked in the focus group meetings. They also received an informed consent form that explained their rights as focus group participants. Focus group participants signed the informed consent form after reading it and received a copy for their files. The original informed consent form stayed with the project coordinator. The signed informed consent forms are kept in a locked filing cabinet in the project coordinator's office at the Center for Disabilities Studies and will be destroyed after two years.

All potential focus group participants were called a day before the focus group session to remind them about the meeting. An answering machine message was left if individuals did not answer the phone.

A script was used to guide each focus group session. The project coordinator led the focus group and an assistant took notes. The focus group sessions were also audio taped. Participants engaged in conversations that touched upon the scripted questions and the project coordinator used the script only to ensure that all questions were addressed.

Audio tapes of the focus group sessions were transcribed. Qualitative data were organized by themes and categories and reported as themes that emerged from the raw data. Section six of this report illustrates the findings from the focus group sessions.

### **Study Limitations**

This small pilot project had some methodological limitations. First, the response rate for the postcard survey in phase I was low but typical of mail surveys. Surveys that rely on a single mailing often 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.

The Phase II extended survey participant pool consisted of individuals from the postcard survey who indicated that they were interested in participating. If they were interested they provided their telephone number and name. This approach might not have been the most effective one for recruiting a maximum number of participants. It was very cumbersome and time consuming to try to reach individuals by phone. Some of the phone numbers were disconnected and individuals who could not be reached by phone could not be given an opportunity to participate in the survey since the research

team did not have mailing addresses for participants. Asking interested participants for to include both their phone numbers and mailing addresses on the post card survey could have generated a larger pool of survey participants. Alternatively, using a single stage survey approach that involved mailing only the extended survey to all 2,000 sample members would have been more efficient and would likely have resulted in a larger data set.

Another limitation of this study is the ethnic/racial composition of the extended survey participants. In that survey almost all participants were white. Since racial/ethnic information was not collected in the postcard survey, it is not known if racial/ethnic diversity was lost between samples I and II or if the project started out with a non-diverse sample. Clearly, more research about transition experiences is needed with a more diverse sample.

The small sample size of the extended survey limits the power of our statistical analysis and the generalizability of our findings. This small pilot sample provides some insight into the experiences young adults and their families have with the transition process; however it does not allow for more general interpretation of the results.

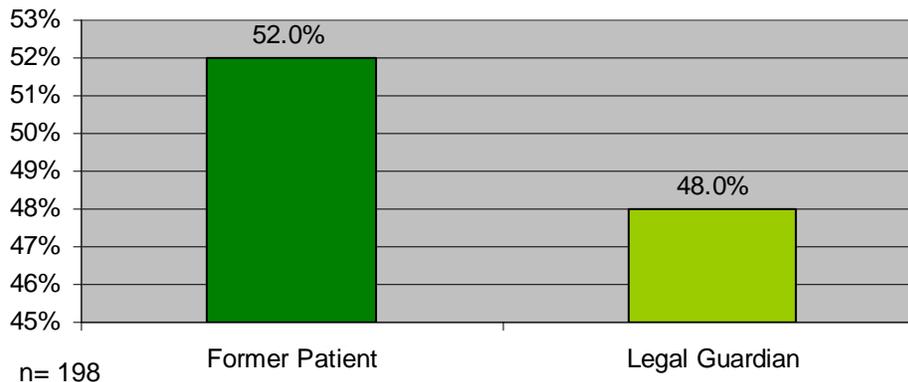
Finally, the extended survey instrument had some flaws. Even though it was pilot tested, results from the actual responses showed that some questions were not clearly written and left room for interpretation of what was asked of the respondents. This was especially true for questions relating to primary care provider and specialist services. Additionally, not all questions provided enough answer categories as shown by questions in which the response rate was highest for "other" reasons rather than the ones listed. A more defined and concisely written instrument may allow for better interpretation of results.

## SECTION 4: FINDINGS OF POSTCARD SURVEY

### Demographic Information

In Phase I, the postcard survey, demographic questions were asked about who completed the survey (former patient or legal guardian); what the former patients' illness, chronic condition, or disability was; and how much time had passed 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 (Figure 4.1.).

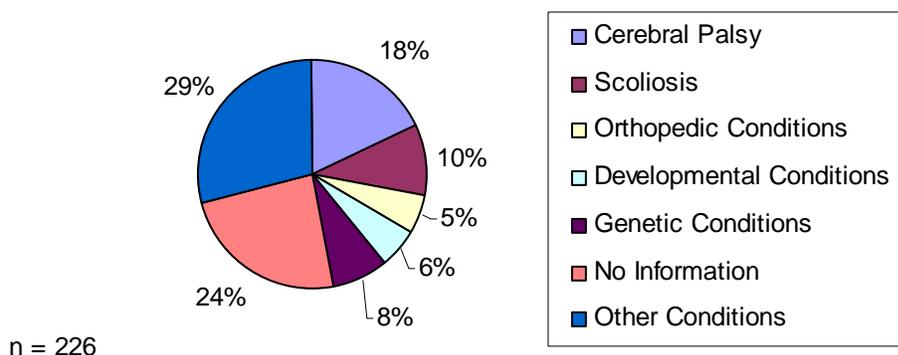
Figure 4.1. Person Completing the Survey



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.

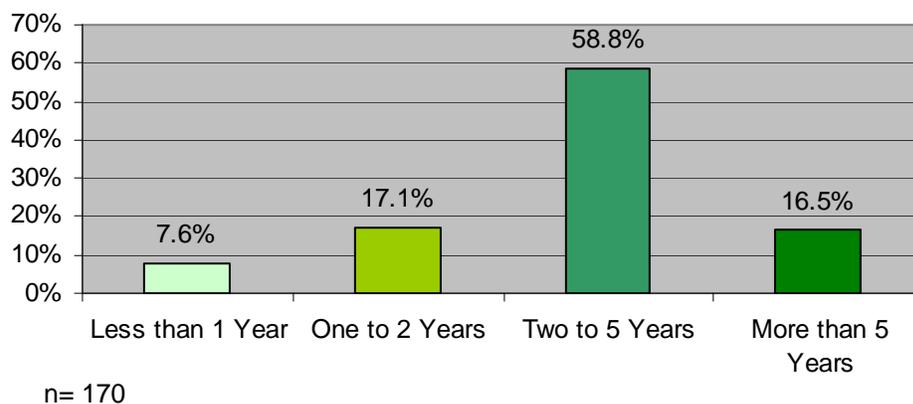
Of the 226 respondents, 18% indicated that their chronic condition was cerebral palsy. Another 10% reported their chronic condition as scoliosis. Almost 25% of the respondents did not indicate a chronic condition, and 29% of the respondents had conditions that were categorized as "other conditions." 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. illustrates the findings in detail.

**Figure 4.2. Former Patients' Chronic Conditions**



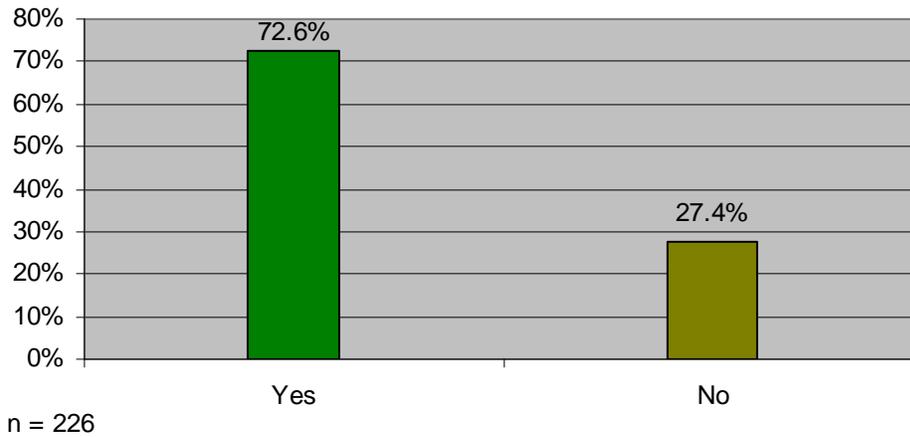
Respondents were also asked how long it had been since they had transitioned from AIDHC services to community-based adult health care. More than half of all participants who answered this question (58.8%) reported that they had left services two to five years ago. Over 17% of the respondents had transitioned 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 (Figure 4.3.).

**Figure 4.3. Time Since Transitioning out of AIDHC**



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.

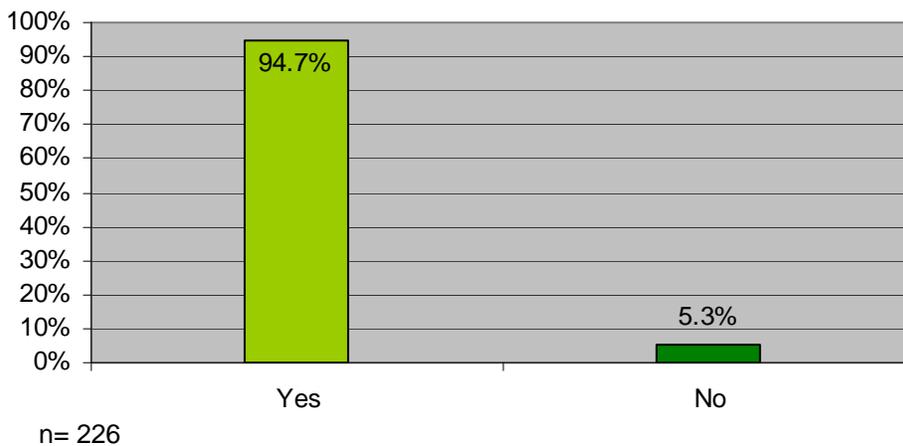
**Figure 4.4. May Contact Participant**



**Having a Primary Care Provider**

The vast majority of respondents (214) reported that they had a primary care provider (PCP), while 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 did not have a PCP.

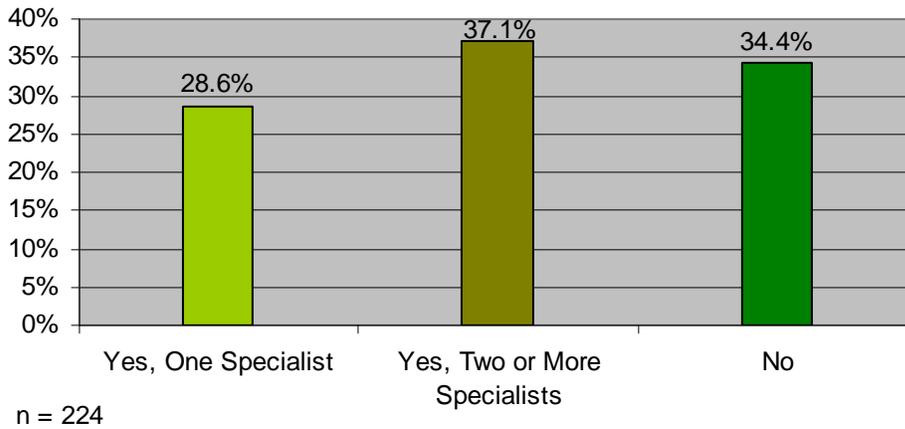
**Figure 4.5. Participant has a Primary Care Provider**



**Having One or More Specialists**

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

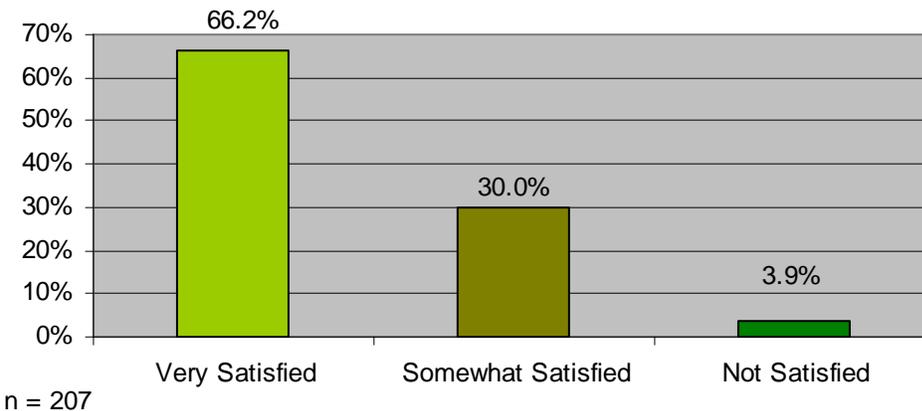
**Figure 4.6. Participant has One or More Specialist(s)**



### **Satisfaction with Primary Care Provider**

The large majority of participants stated that they were very satisfied (66.2%) with their primary care provider (PCP). However, 30% of participants were only somewhat satisfied, and 3.9% of respondents were not satisfied with their PCP (Figure 4.7.).

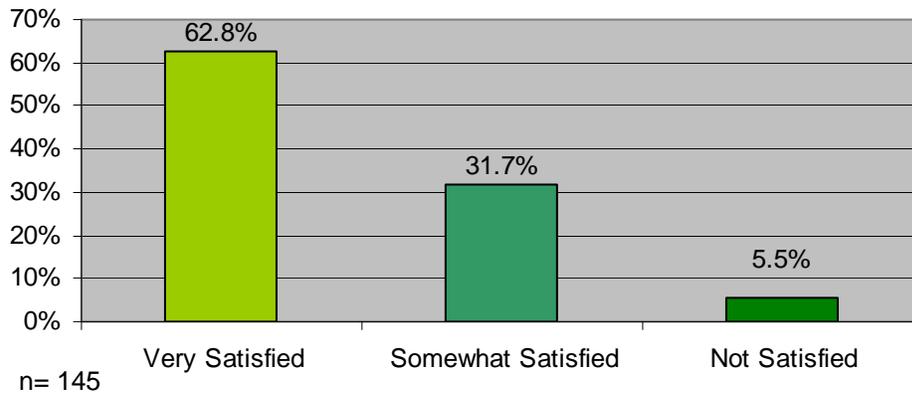
**Figure 4.7. Satisfaction with Primary Care Provider**



### **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 (Figure 4.8.) 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**

| <b>Not Finding the Right Physician</b>  | <b>Disability as an Obstacle to Transition</b>   | <b>Satisfaction with Pediatric Services</b>   | <b>Other</b>   |
|---|--|---|--|
| <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 medical 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: FINDINGS OF EXTENDED SURVEY

In Phase II, the extended survey, participants were asked questions about their backgrounds, access to and utilization of care, satisfaction with primary care provider and specialist services, insurance coverage, comparison of the pediatric and adult systems, and overall transition experience. The following sections illustrate the findings of the extended survey<sup>1</sup>.

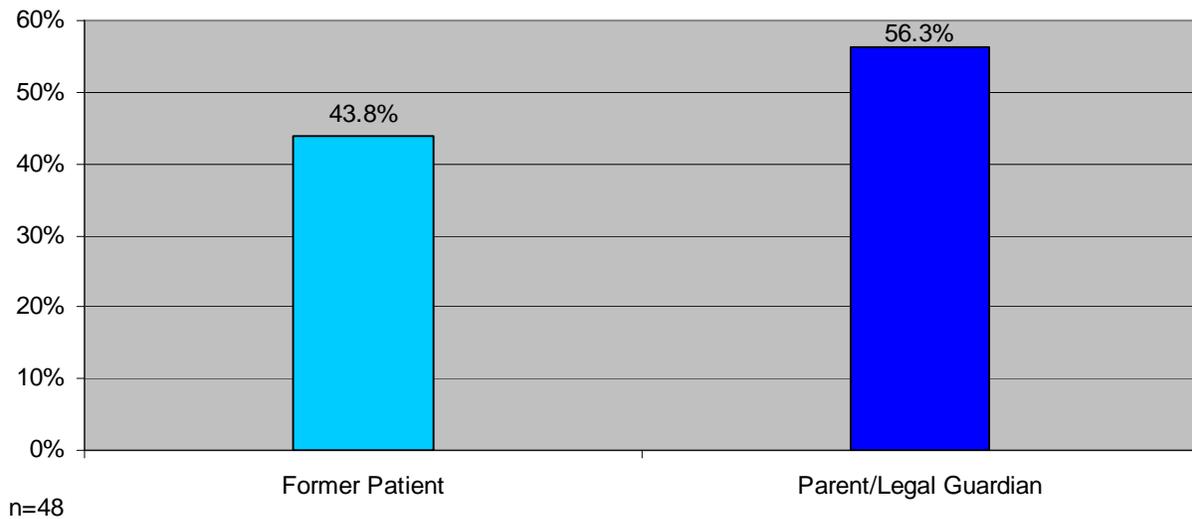
### Demographic Information

Participants were asked if the former patient or a parent/legal guardian completed the survey, the age, gender, and ethnicity of the former patient, the former patient's primary health condition, how long ago the transition from Alfred I. duPont Hospital for Children's pediatric services into adult services occurred, and about the former patient's current living arrangements.

### Survey Respondents

Almost 44% of individuals who completed the extended survey were former patients and 56% were parents or legal guardians (Figure 5.1.). This is the reverse of the postcard survey, in which more former patients and fewer parents/legal guardians completed the survey.

Figure 5.1. Person Completing Extended Survey

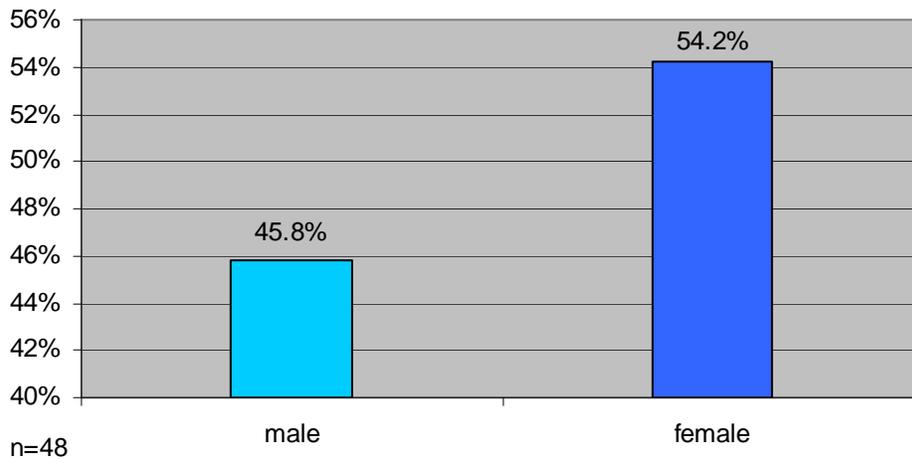


<sup>1</sup> The focus of the extended survey is on former AIDHC patients. The results that follow pertain to this group of people, which includes former patients who answered the survey questions directly and parent/legal guardian respondents. Parents/legal guardians answered for those former patients who could not due so by themselves because of severe or profound intellectual disability. For the sake of clarity and brevity the terms 'former patients', 'patients', and 'parents'/legal guardians' are used to refer to this target population.

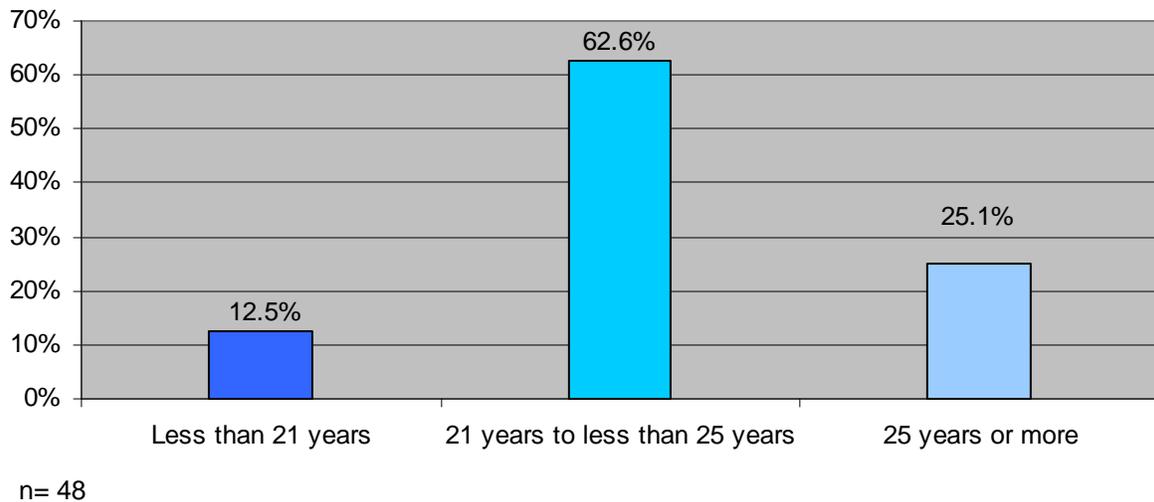
Gender, Age, and Ethnicity

Of all former patients, 45.8% were male and 54.2% were female (Figure 5.2.). Patient age was divided into three subcategories: younger than 21 years of age, 21 years to less than 25 years of age, and 25 years of age or older. The largest group was the 21 to 24 year old group (62.6%), followed by the 25 years or older group (25.1%) and the under 21 years group (12.5%) (Figure 5.3).

**Figure 5.2. Gender of Former Patients**



**Figure 5.3. Current Age of Former Patients**

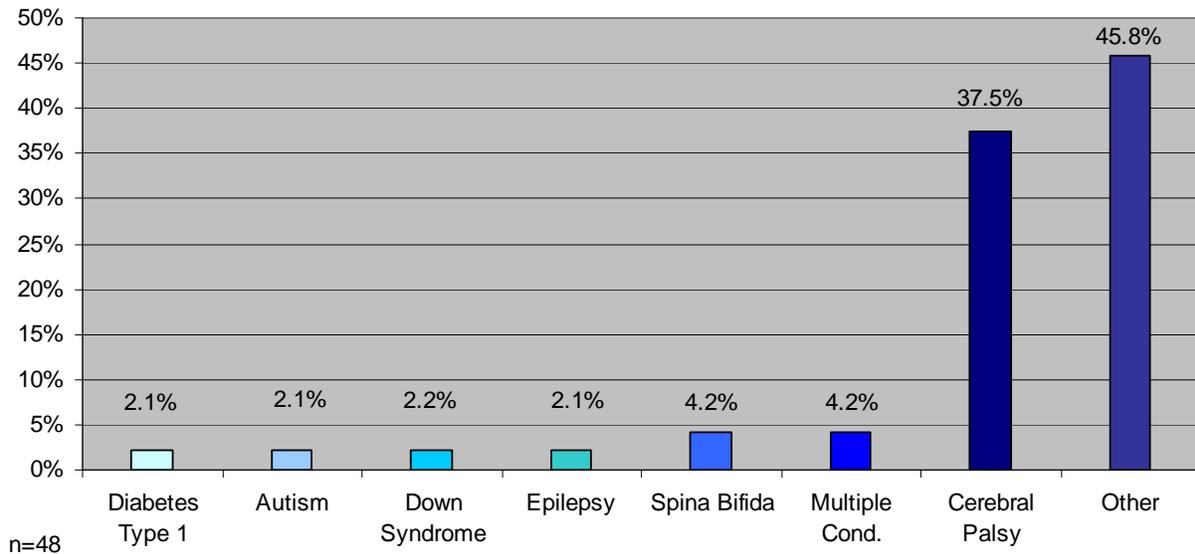


The response sample of the extended survey consisted of almost completely white respondents (93.6%), with one Black/African American respondent and one Hispanic respondent who identified him/herself as Guamanian or Chamorro.

### Primary Medical Condition or Disability

Survey participants reported a large variety of medical conditions and disabilities. The most commonly reported primary single health condition experienced by former patients was “Cerebral Palsy” (37.5%). However, “Other” was the most frequently reported category (45.8%) for former patients (a list of conditions reported under “Other” is available in Appendix B). Small groups of respondents reported ‘Spina Bifida’ and ‘Multiple Conditions’ (both 4.2%). The complete range of conditions is illustrated in Figure 5.4.

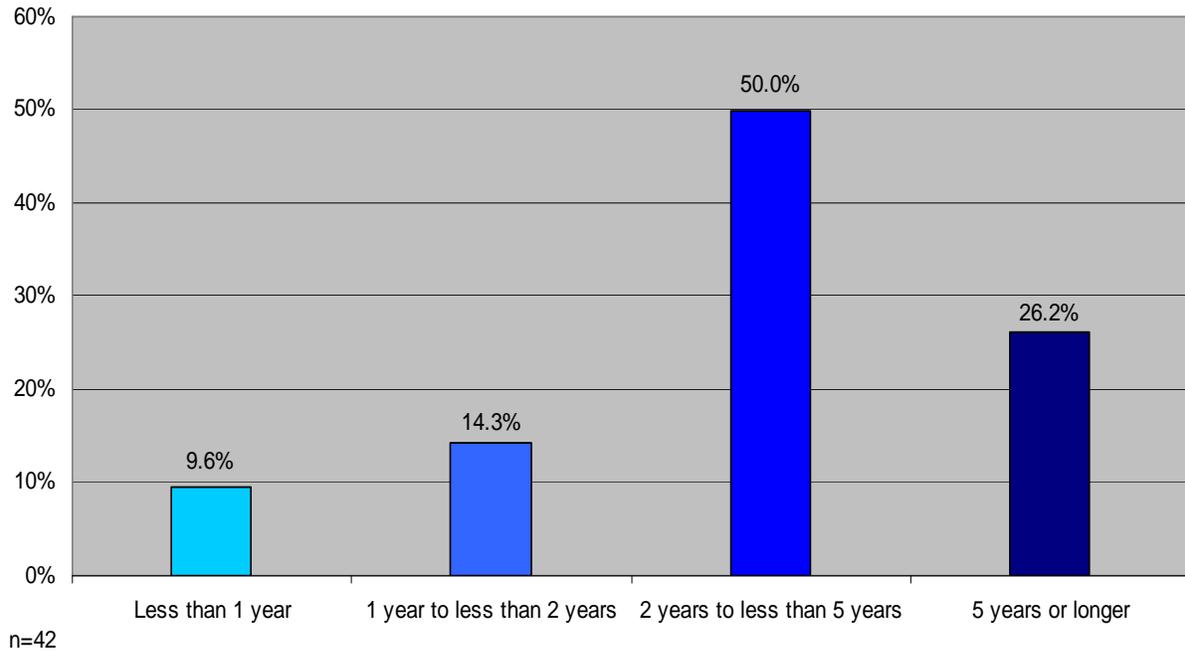
**Figure 5.4. Primary Health Conditions of Former Patients**



### Time since Transition

Study participants were asked how long ago transition from pediatric services at Alfred I. duPont Hospital for Children and other pediatric providers to the adult health care system occurred. Responses were divided into four subcategories; less than one year, one year to less than two years, two years to less than five years, and 5 years and longer. The largest former patient group transitioned between two and five years ago, followed by those who transitioned 5 years ago or longer. The smallest patient group transitioned less than a year ago from pediatric services (Figure 5.5).

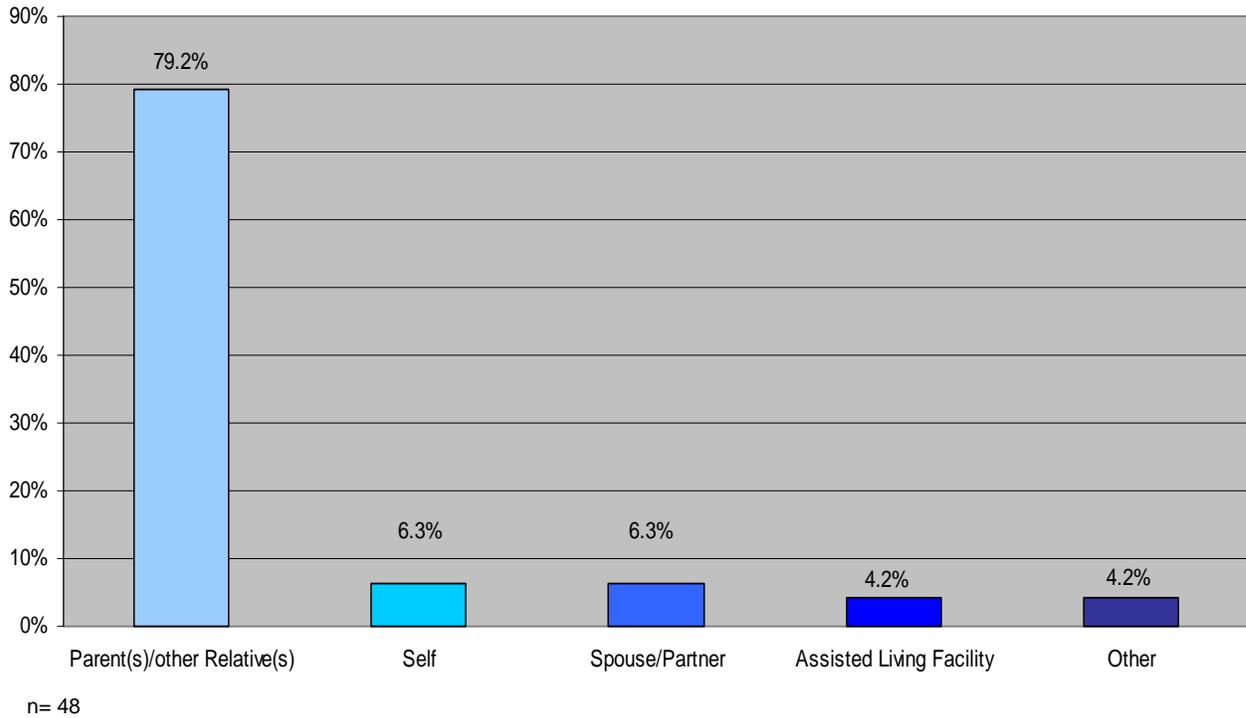
Figure 5.5. Time since Transition



#### Current Living Arrangements

The research team was also interested in learning about former patients' current living arrangements. A large majority of former patients still live with their parents or other relatives (79.2%). Other reported living arrangements include living by oneself (6.3%), living with a spouse/partner (6.3%), living in an assistant living facility (4.2%), and other (4.2%) (Figure 5.6.).

Figure 5.6. Former Patients' current Living Arrangements



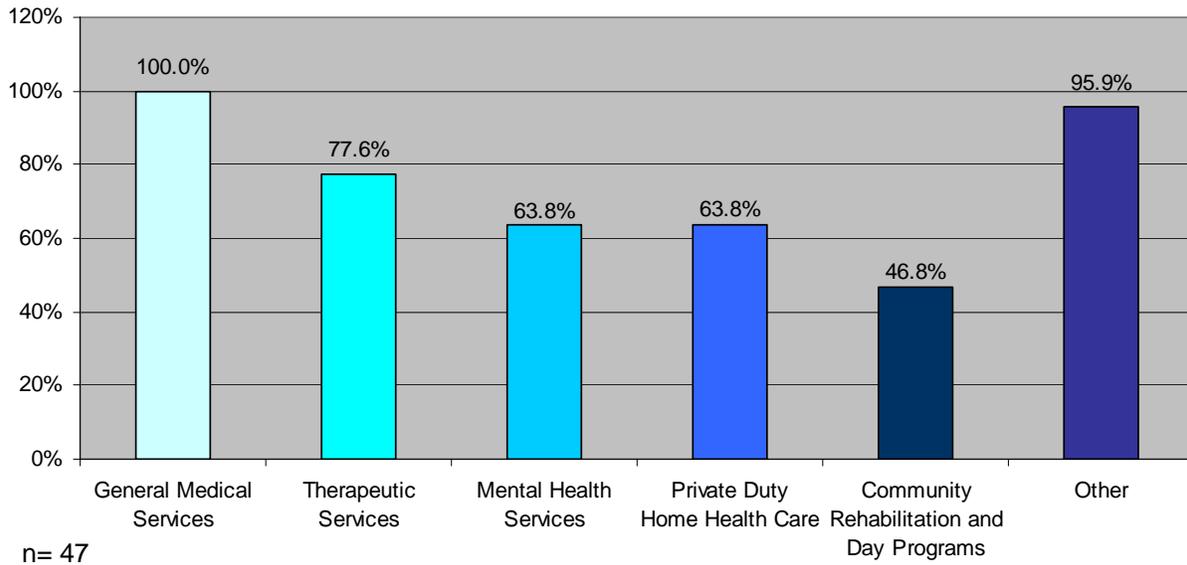
### **Access and Utilization of Adult Health Care Services**

When looking at the transition research literature, access to care is one area that many individuals report as being difficult. Challenges faced include finding appropriate health care services and providers, transportation to providers and services, and accessing the services providers offer. In the extended survey, the research team asked survey participants about services that are available in their communities and which of these services are used and about the length of commute to adult physicians compared to that for pediatric physicians.

#### **Adult Services Currently Available**

Many young adults continue to have various health care needs after they transition out of the pediatric health care system. Therefore, it was of special interest to gather information about the types of health services that are available to young adults in the community and which ones are used by former patients. Figure 5.7 illustrates which services respondents identified as being available in the community.

Figure 5.7. Services currently available to Former Patients

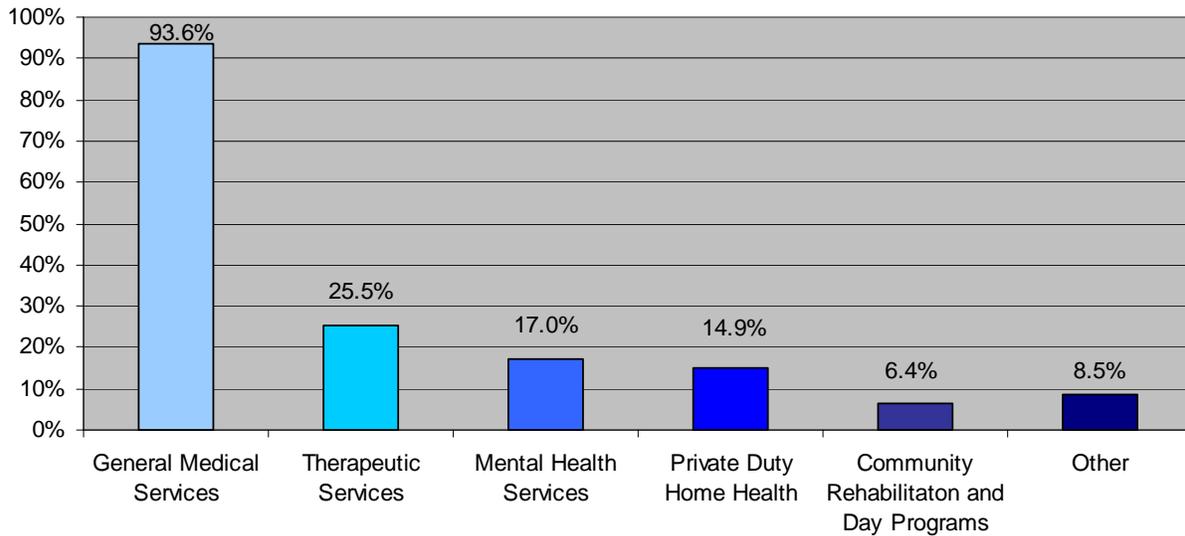


General medical services were reported as available by all survey respondents and 77.6% reported that therapeutic services were available. However, only 63.8% of participants reported that mental health services and private duty home health care are available in their communities. Interestingly, only 46.8% of participants stated that adult community rehabilitation and day programs are available in their communities.

#### Adult Services Currently Used

Figure 5.8 illustrate which services of the ones available in participants' communities are currently used by transitioned patients. Almost all former patients use general medical services (93.6%) and a quarter use therapeutic services (25.5%). These services are followed by mental health (17.0%) and private duty home health services (14.9%).

**Figure 5.8. Services currently used by Former Patients**

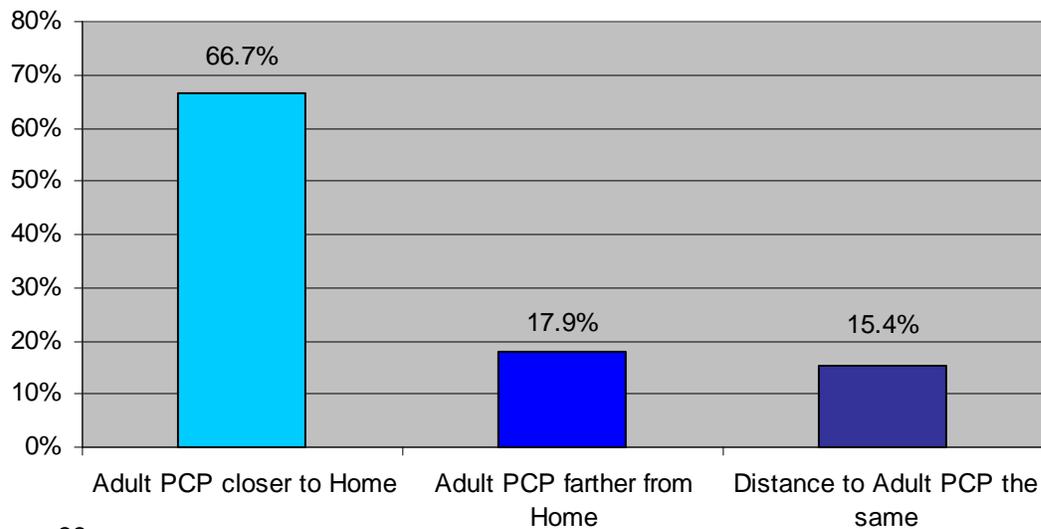


n= 47

Commute to Adult Physicians

When former patients were asked to compare the length of the commute to their adult primary care provider (PCP) to the commute to their former pediatric PCP, a majority of respondents (66.7%) reported that the current commute is shorter (Figure 5.9). However, almost 18% reported that the commute to the PCP is now longer. For 15.4% of all respondents the commute is approximately the same.

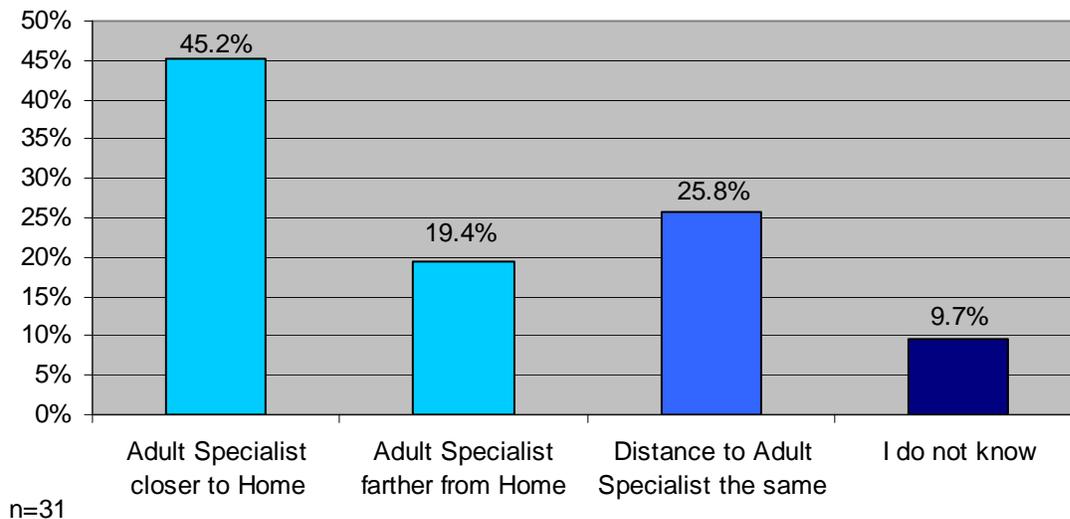
**Figure 5.9. Commute to Primary Care Provider**



n= 39

When former patients were asked to compare the length of their commute to the adult specialist that they see most often to the commute to their former pediatric specialist, a large minority (45.2%) reported that the current commute is shorter and almost 25.8% reported that the commute to the current specialist is approximately the same as to the pediatric specialist (Figure 5.10). However, 19.4% stated that the commute to the adult specialist is longer. Almost 10% were not sure if the commute was longer, shorter, or approximately the same.

**Figure 5.10. Commute to Specialist**



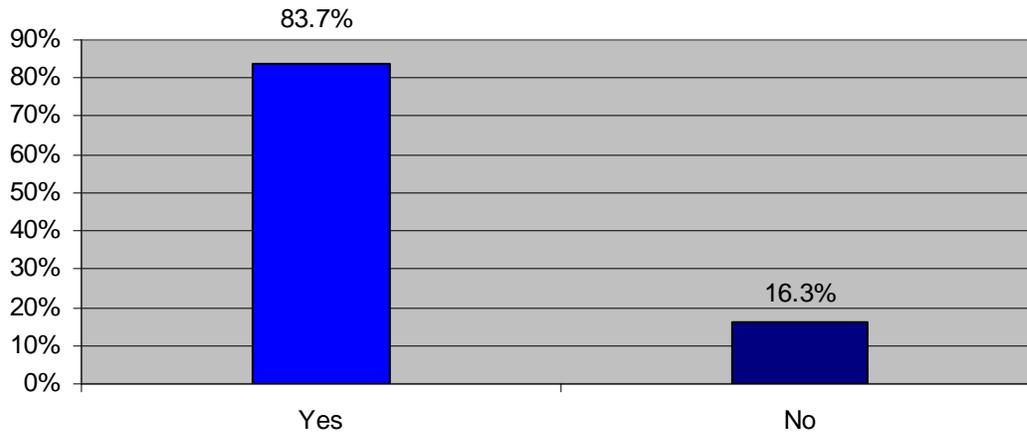
**Access to Primary Care Providers (PCP) and Specialists**

For some individuals with chronic health conditions or disabilities it can be challenging to find health care providers or to utilize health care providers due to transportation issues. In this survey, participants were asked if they currently have a primary care provider (PCP) and if they have a specialist(s). If they responded that they did not have access to a doctor they were asked about the reasons for not having a PCP or specialist.

Access to PCP

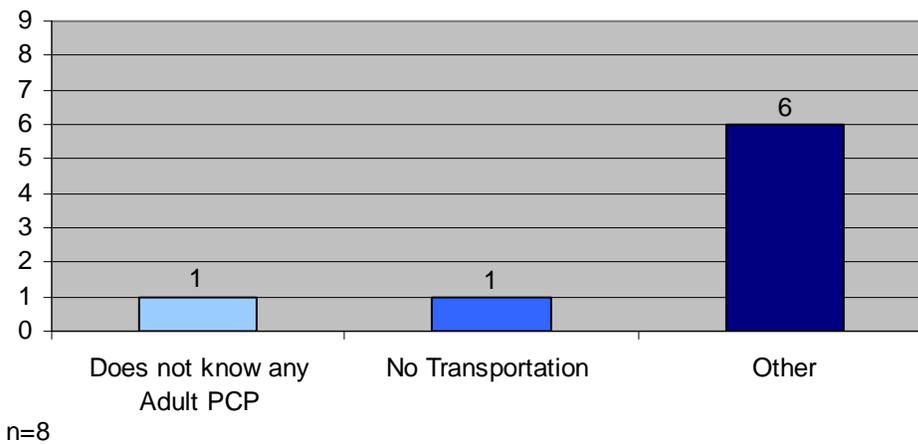
The extended survey asked participants if former patients currently have a primary care provider (PCP) who provides services to them. A total of 83.7% reported that the patient has a PCP and 16.3% do not have a PCP (Figure 5.11).

**Figure 5.11. Does Former Patient currently have a Primary Care Provider**



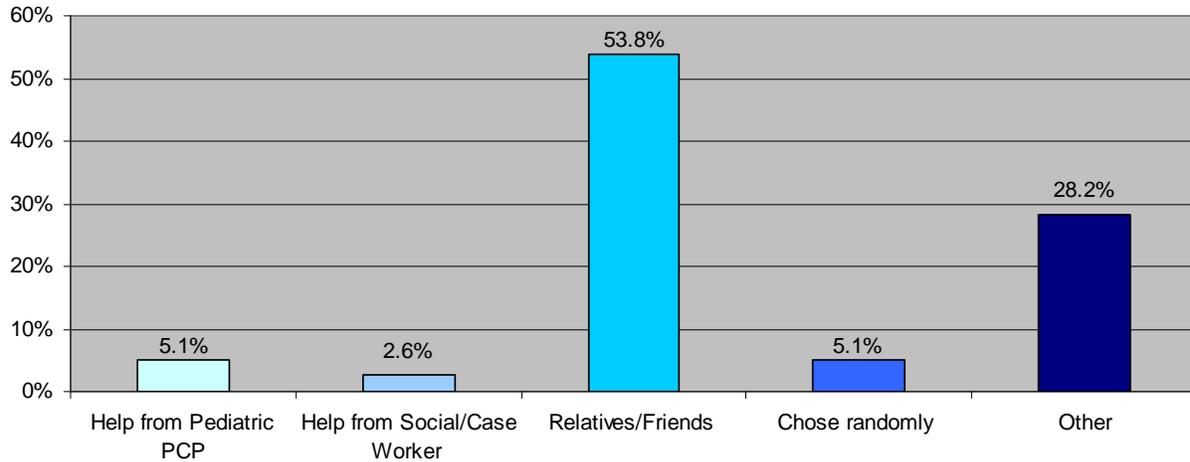
Of the eight respondents who indicated that they did not have a PCP, one person said that he/she did not know any adult primary care providers, another person reported that transportation to a PCP was an issue, and six former patients indicated other reasons for not having a PCP (see Figure 5.12.).

**Figure 5.12. Reason why Former Patient does not have Primary Care Provider**



The research team was also interested in finding out how survey participants who reported that they have an adult PCP identified their current doctor. The majority of participants (53.8%) indicated the adult PCP was found through referral by relatives or friends (Figure 5.13.). More than 5% indicated the PCP was chosen randomly from the phonebook/webpage/advertisement, 5.1% indicated that help from the pediatric PCP, and 2.6% reported that a social worker/case manager identified the PCP.

**Figure 5.13. How Former Patient identified Primary Care Provider**

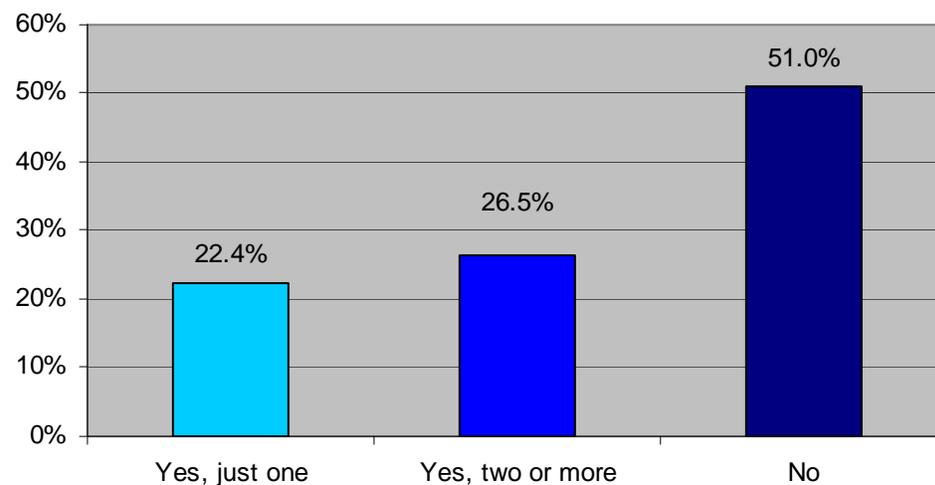


n= 49

Access to Specialist(s)

The same questions that were asked about PCPs were also asked regarding specialist services. A total of 48.9% of former patients receive specialist care, with 22.4% seeing one specialist and 26.5% receiving services from two or more specialists (Figure 5.14.). (For a complete list of specialists that former patients identified please see Appendix C).

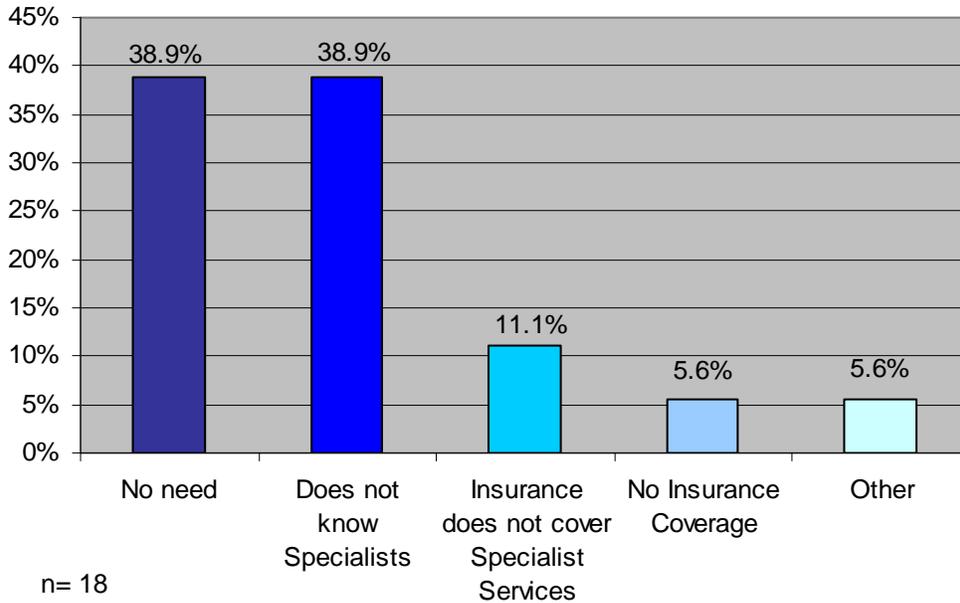
**Figure 5.14. Does Former Patient currently see Adult Specialist(s)**



n=49

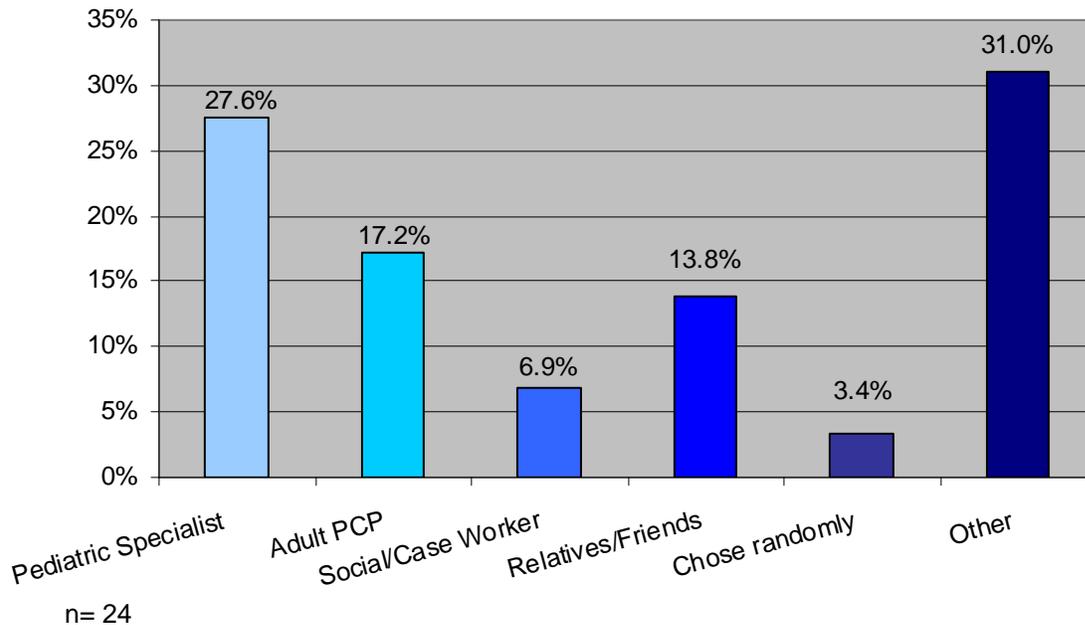
Of the 51% of patients who do not receive specialist care, 38.9% reportedly did not currently need specialist services, 38.9% reported that they do not know the specialists they need, the insurance of 11.1% does not cover the specialist services they need, and 5.6% do not have any health insurance that could help pay for specialist services (Figure 5.15.).

**Figure 5.15. Reasons for not having Adult Specialist(s)**



When asked about how former patients who had one or more specialists identified their specialist(s), 27.6% reported that the pediatric physician helped identify him/her, 17.2% stated that the adult physician identified him/her, and 13.8% said that relatives or friends identified him/her. Other answers included that the social/case worker had identified the specialist; that former patients chose him/her randomly from the phone book/webpage/advertisement; and that other avenues were used to identify the specialist (Figure 5.16.)

Figure 5.16. How Former Patient identified Adult Specialist(s)



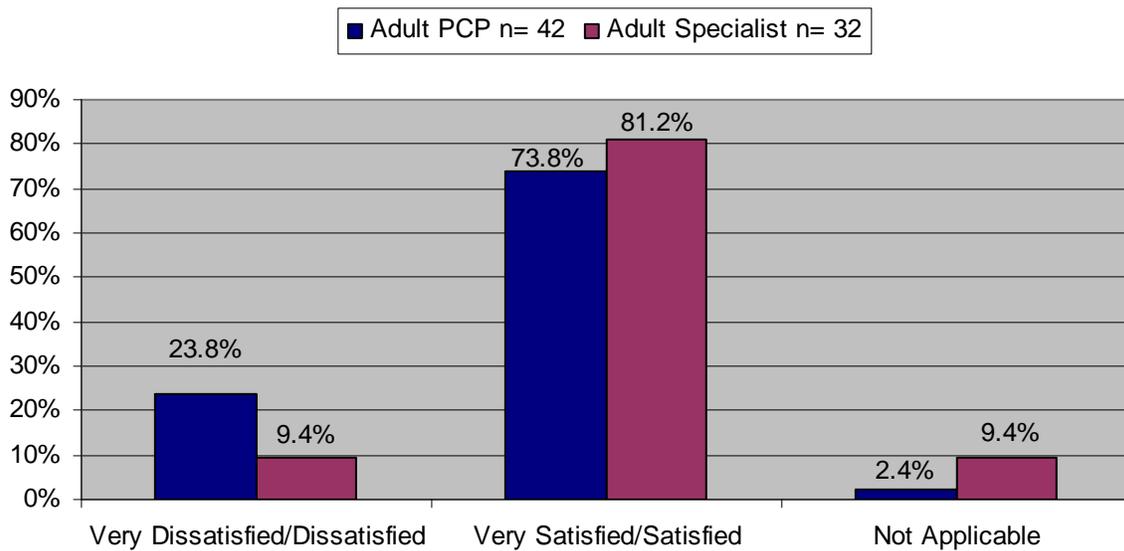
### **Satisfaction with Care**

One of the three research questions for this study addressed the issue of satisfaction with care in the adult health care setting. Specific questions regarding overall satisfaction with care, satisfaction with referrals, adult health care providers' knowledge on the former patients' health condition or disability, examination time, and willingness to prescribe medication were asked. Questions about satisfaction were broken down by satisfaction with primary care provider services, specialist services, and in comparison to satisfaction with the pediatric services former patients' received from PCPs and specialists.

#### **Overall Satisfaction with Primary Care Provider (PCP) and Specialist(s)**

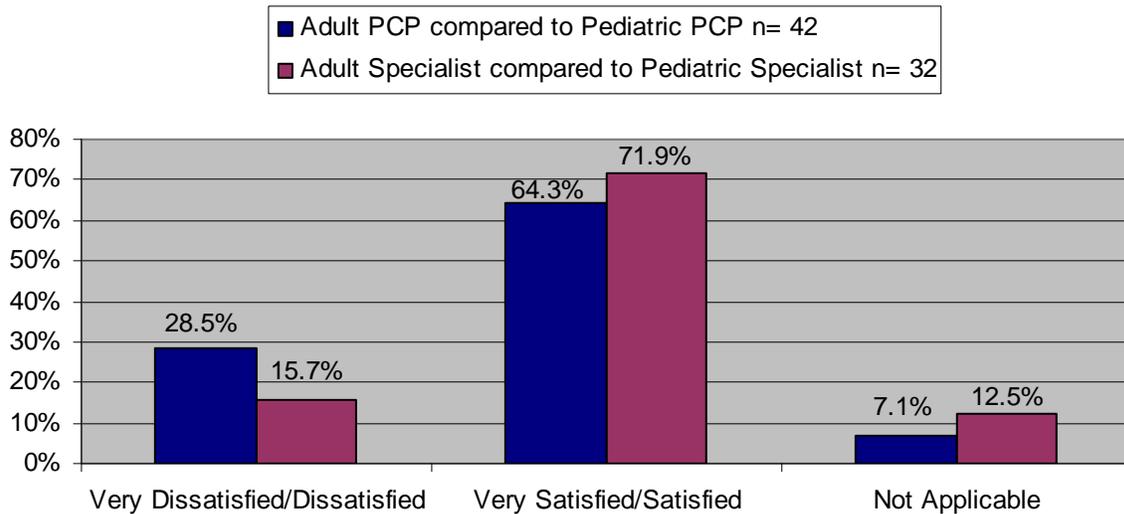
Overall, former patients appeared to be satisfied with their adult primary care providers and specialists. However, almost a quarter of respondents (23.8%) were very dissatisfied or dissatisfied with their PCP and almost 10% were very dissatisfied or dissatisfied with their specialist(s) (Figure 5.17.).

**Figure 5.17. Overall Satisfaction with PCP and Specialist(s)**



When comparing satisfaction of adult physicians with former patients' satisfaction with their pediatric physicians, satisfaction rates for adult PCPs dropped slightly to 64.3%. Similarly, satisfaction rates for adult specialists dropped to 71.9% (Figure 5.18.).

**Figure 5.18. Comparison of Satisfaction with Services provided by Adult Physicians versus Pediatric Physicians**

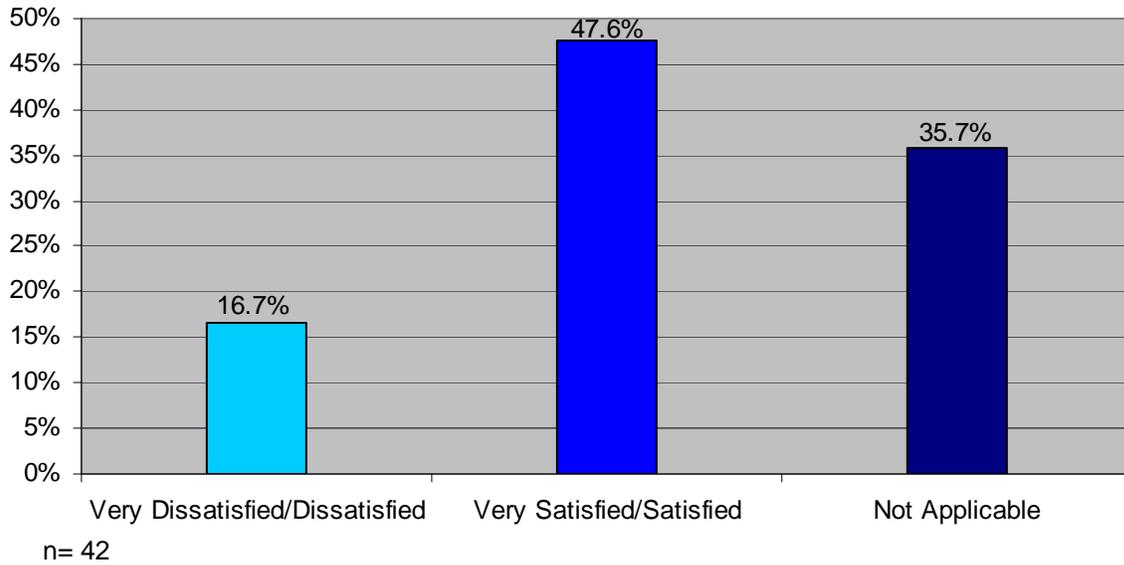


**Satisfaction with Referral Services by Adult Primary Care Provider**

One of the specific satisfaction questions addressed former patients' satisfaction with their adult PCP's willingness to write referrals to specialists. Almost 17% reported that they were very dissatisfied or dissatisfied with receiving referrals from their PCP. A

total of 47.6% were very satisfied or satisfied and 35.7% reported that this was not applicable to their situation (Figure 5.19.).

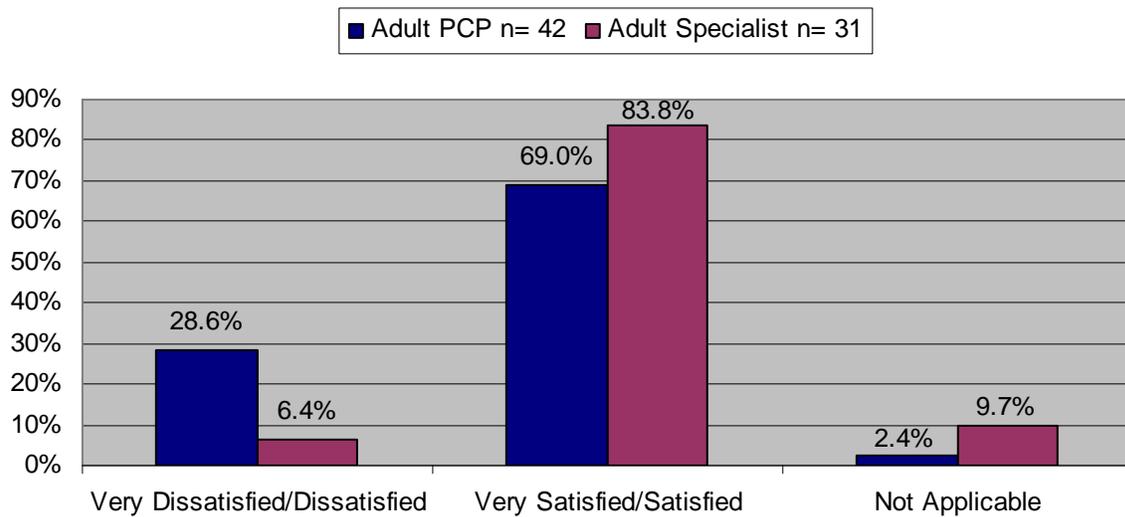
**Figure 5.19. Satisfaction with Referrals by Adult PCP**



**Satisfaction with Physicians' Knowledge about Patient's Health Condition**

As more patients with pediatric health conditions survive into adulthood, one concern is that adult primary care providers and specialists may not know and understand these patients' conditions well and may, therefore, experience challenges in treating these patients. Survey respondents were asked if they were satisfied with their current PCP's and specialist(s)'s knowledge about their specific health condition or disability. Regarding PCPs' knowledge about former patients' health conditions, almost 29% reported that they were either very dissatisfied or dissatisfied. However, only a small number (6.4%) of former patients were dissatisfied with their specialists' knowledge about their health condition (Figure 5.20).

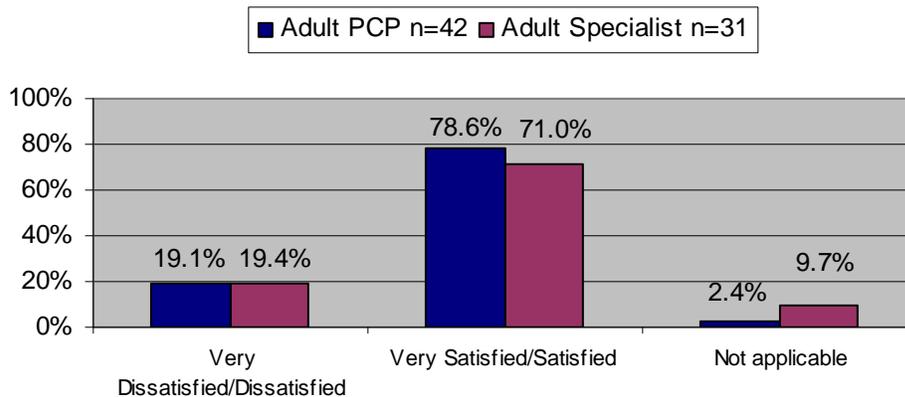
**Figure 5.20. Satisfaction with Adult Physicians' Knowledge about Patients' Health Conditions**



Satisfaction with Adult Physicians' Examination Time

One complaint that some adult patients voiced is that physicians in the adult health care system do not take enough time in examining their patients. The survey asked participants about their satisfaction with the time their PCPs and specialists take to examine them. Findings showed that 19.1% of former patients were either very dissatisfied or dissatisfied with the time their current PCP took to examine them while 19.4% were dissatisfied (no one reported that they were very dissatisfied) with the time their specialist(s) took to examine them (Figure 5.21.).

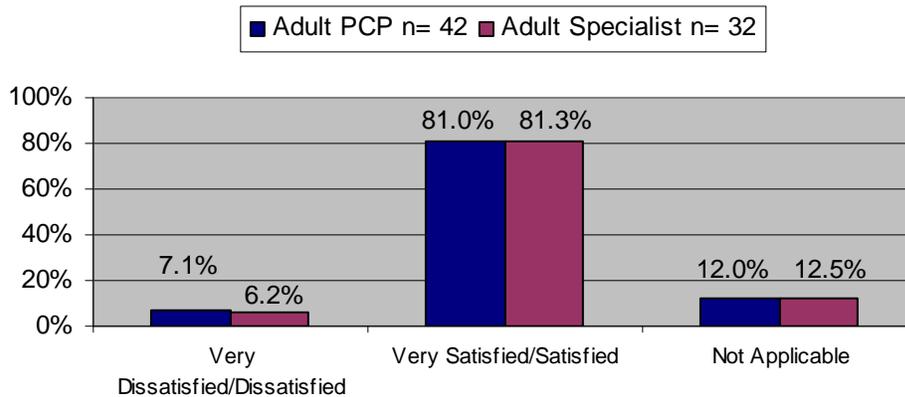
**Figure 5.21. Satisfaction with Physicians' Examination Time of Patient**



### Satisfaction with Physicians' Willingness to Prescribe Medication

Some patients leave the pediatric health care setting equipped with a variety of medications that the patients know work for their conditions. With changes in insurance coverage and physicians one might expect to see challenges in receiving prescriptions for medications that patients received in the pediatric setting. Based on this assumption the research team asked survey participants about their satisfaction with their physicians' willingness to prescribe the medications that the former pediatric patient knows work for him/her. In this survey 81.0% of former patients were very satisfied or satisfied with their PCP's willingness to prescribe medications and 81.3% of patients who had a specialist(s) were very satisfied or satisfied with their specialist(s) willingness to prescribe medications. Seven percent of participants were very dissatisfied or dissatisfied with their PCP's willingness to prescribe medications but only 6.2% were either very dissatisfied or dissatisfied with their specialist(s) willingness (Figure 5.22.).

**Figure 5.22. Satisfaction with Physicians' Willingness to Prescribe Medication**



### Collaboration between Pediatric and Adult Physicians

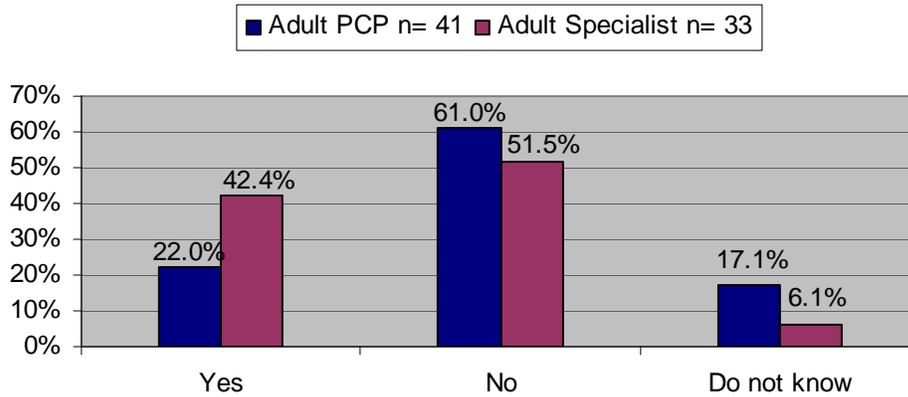
Recent literature on the issue of transition shows that families often feel that they were not well prepared for the transition experience by their physicians and that there was no communication between their pediatric and adult doctors. This survey asked specific questions about the collaboration efforts of pediatric physicians and their adult colleagues. Questions asked if pediatric physicians helped patients with their transition to the adult health care services, if pediatric physicians provided medical records to their adult colleagues, and if information sharing between pediatric and adult physicians did or could improve the services the patient receives.

#### Help with Transition Process

The research team was interested in finding out if survey participants received help from their pediatric physicians with the transition process. Sixty-one percent of respondents stated that they did not receive such help and 51.5% of survey participants who had a specialist reported that they did not receive such help (Figure 5.23.).

Interestingly, 17.1% reported that they did not know if their PCP helped them with the transition, and 6.1% of participants did not know if their specialist helped them.

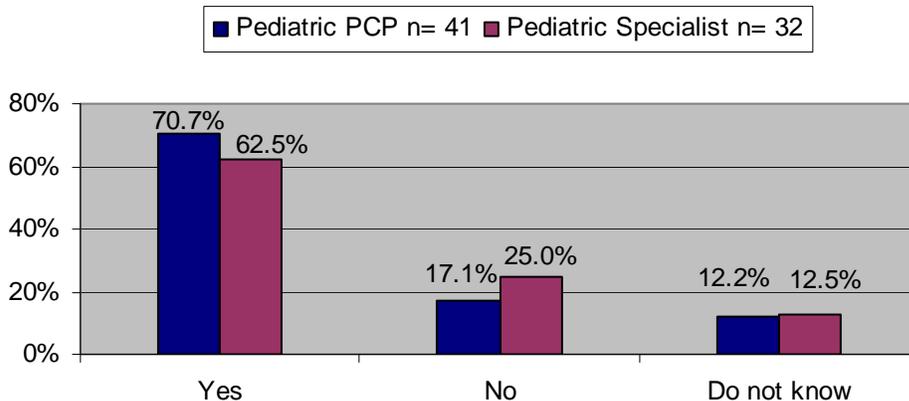
**Figure 5.23. Did Pediatric Physicians help with Transition to Adult Physicians**



Providing Medical Records

When patients transition from the pediatric to the adult health care system, many have acquired an extensive record of treatments, hospitalizations and medications. Medical records of previous conditions and treatments may be helpful to new providers in determining the appropriate continuation of treatment for patients. The research team wanted to know if the pediatric PCPs and specialists provided their patient’s medical records to the new health care providers. The majority of pediatric PCPs (70.7%) and specialists (62.5%) provided the medical records to the adult providers; however, 17.1% of survey participants reported that the PCP did not provide medical records to the adult providers and a quarter of respondents stated that the specialists did not provide records to the new specialists (Figure 5.24.).

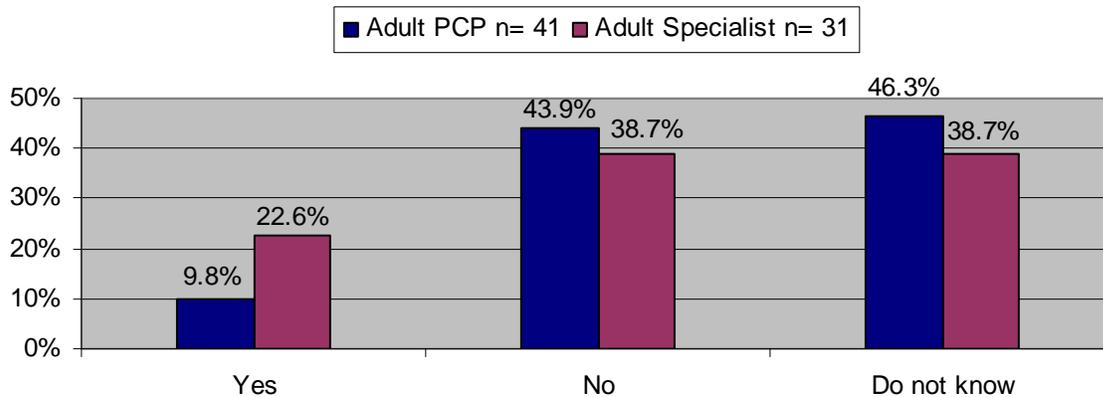
**Figure 5.24. Pediatric Physicians Provided Medical Records to Adult Physicians**



### Contact between Adult Physicians and Pediatric Physicians

The research team was also interested if adult physicians reached out to their pediatric colleagues to gain more information or a better understanding of their patients' health condition, illness, or disability. A large percentage of survey participants reported that they did not know if their adult PCP (46.3%) or specialist(s) (38.7%) contacted their pediatric physicians; however 43.9% stated that their adult PCP did not contact their former pediatric PCP and 38.7% of participants who receive specialist care said that their adult specialist did not contact their pediatric specialist to get more information (Figure 5.25.).

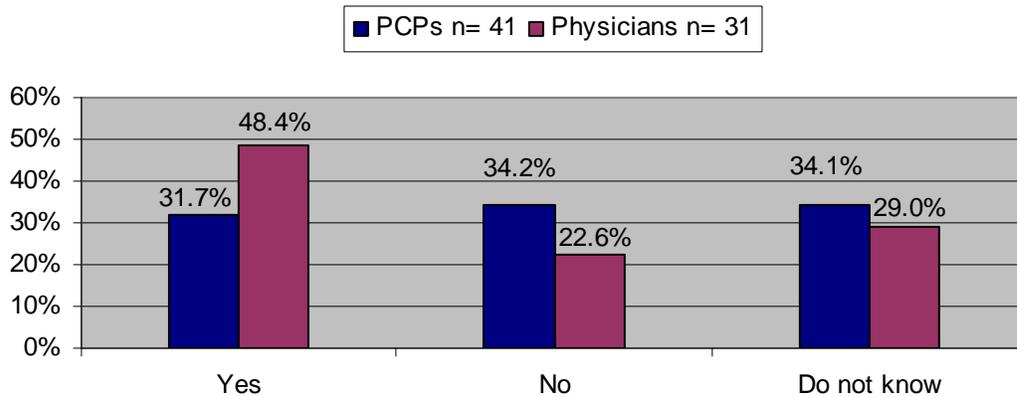
**Figure 5.25. Contact between Adult Physicians and Pediatric Physicians to gain more Information on Patient's Condition**



### Sharing Information to Improve Current Services

One could assume that services could be improved if pediatric and adult physicians worked together to make sure all relevant information is shared. The survey asked participants if they thought adult health care services could be improved (and in cases where participants knew that their adult and pediatric physicians shared information participants were asked if services did improve) if information was shared between pediatric and adult physicians. For PCPs, survey participants were almost equally divided with their responses: 31.7% thought that that sharing information could improve services, 34.1% said that it would not improve services, and 34.1% reported that they did not know if it would improve services. Of the participants who received specialist services, almost 49% thought that sharing information would improve services, 22.6% did not think it would improve services, and 29% reported that they did not know if it would improve the services they currently receive from their adult specialists (Figure 5.26.).

### 5.26. Could/did sharing Information between Pediatric and Adult Physicians improve current Medical Care



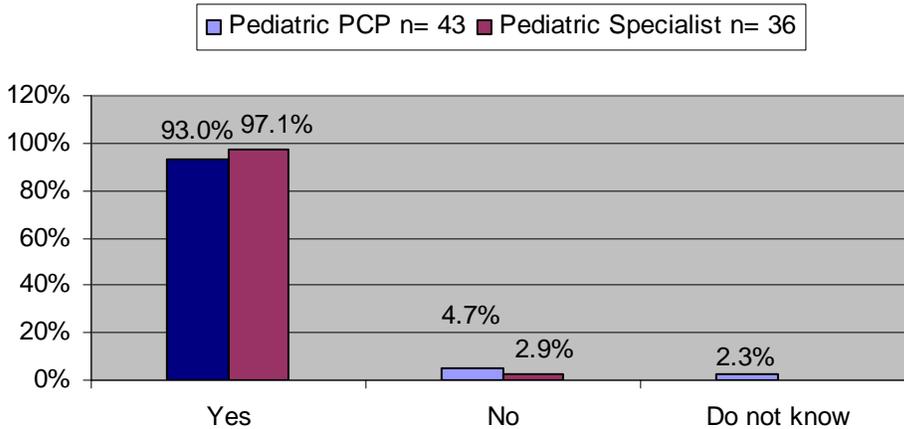
### Partnership between Patients and Physicians

In order to optimize medical interventions and to increase success of treatment or maintenance of a condition, it is important that patients and physicians work together in a collaborative effort. Patient collaboration may be achieved if patients feel that they can trust their physicians and if they feel supported and heard by their health care providers. In the survey, participants were first asked about their relationships with their pediatric physicians. The survey asked participants if they trusted their physicians, if they felt supported, heard, and respected and if they felt that their pain management was appropriate (if applicable). In addition, participants were then asked to compare their relationship that they have had with their pediatric physicians to the relationship they currently have with their adult physicians.

#### Relationship with Pediatric Physicians

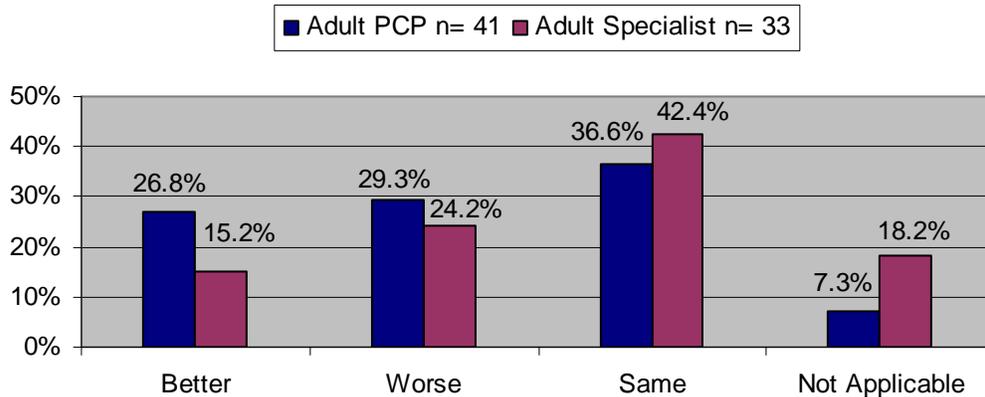
When asked if they have had a trusting relationship with their pediatric primary care provider (PCP), participants answered overwhelmingly (93.0%) with 'yes.' This also holds true when asked about their relationship with pediatric specialist(s) (97.1%) (Figure 5.27.).

**Figure 5.27. Trusting Relationship with Pediatric Physicians**



When asked to compare their relationship with their pediatric PCP to the relationship they currently have with their adult PCP, 36.6% said that the relationship was the same, 29.3% reported that it was worse now, and 26.8% stated that it was better now. Looking at the comparison of the relationship with the pediatric specialist to the adult specialist 42.4% reported that the relationship was the same; 24.2% said that it was worse, and only 15.2% said that it was better (Figure 5.28.).

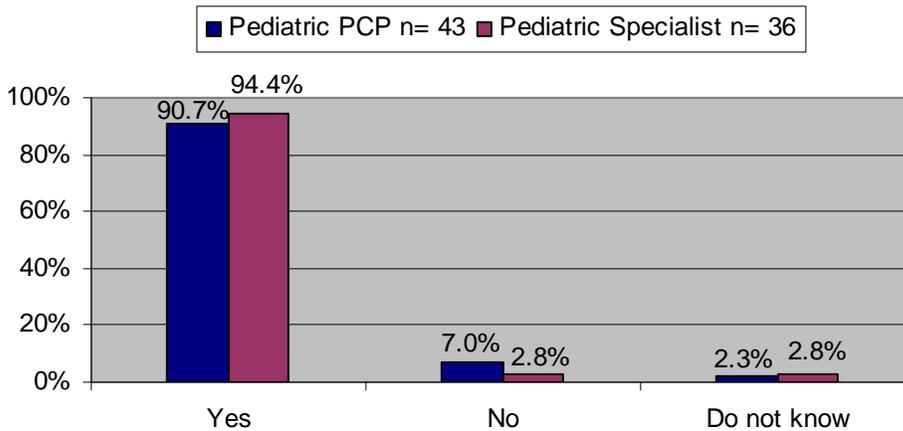
**Figure 5.28. Current Relationships with Adult Physicians compared to Relationships with Pediatric Physicians**



Support from Physicians

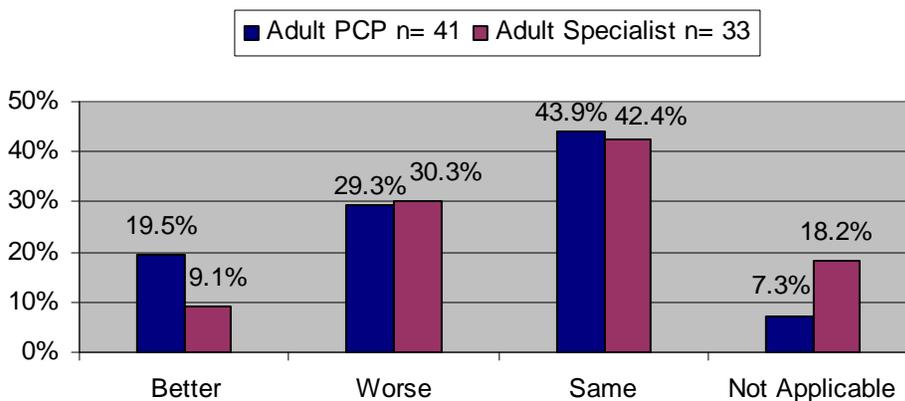
Participants were asked if they felt supported and respected by their pediatric PCP. Again, over 90% of participants reported that their pediatric PCP was supportive, and 94.4% of all respondents with pediatric specialist(s) said that they were supported (Figure 5.29.).

**Figure 5.29. Pediatric Physicians supportive of Patient**



In comparison to their pediatric PCP colleagues, only 19.5% of respondents thought that the adult PCP was better, 43.9% thought they were the same regarding the support they offered, and 29.3% reported that their current PCP's support was worse compared to the support they had received from the pediatric PCP. For the comparison regarding support from specialist(s), 42.4% felt that the support was the same, 30.3% of respondents reported that support was worse now, and 9.1% said that support was better now (Figure 5.30.).

**Figure 5.30. Support provided by Adult Physicians compared to Pediatric Physicians**

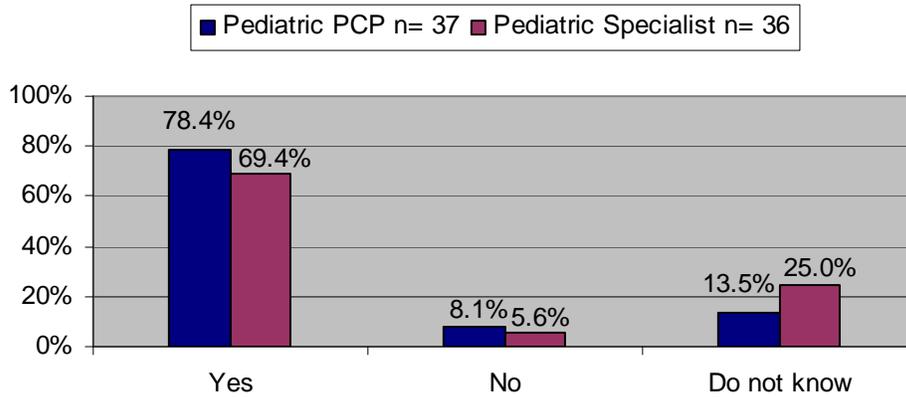


### Pain Management

Survey respondents were asked if they were satisfied with the pain management that their pediatric PCP and pediatric specialist had provided to them. Over 78% of respondents stated that they were satisfied with the pain management they received from their pediatric PCP and 69.4% of respondents were satisfied with the pain management through their pediatric specialist. For a quarter of respondents who had a

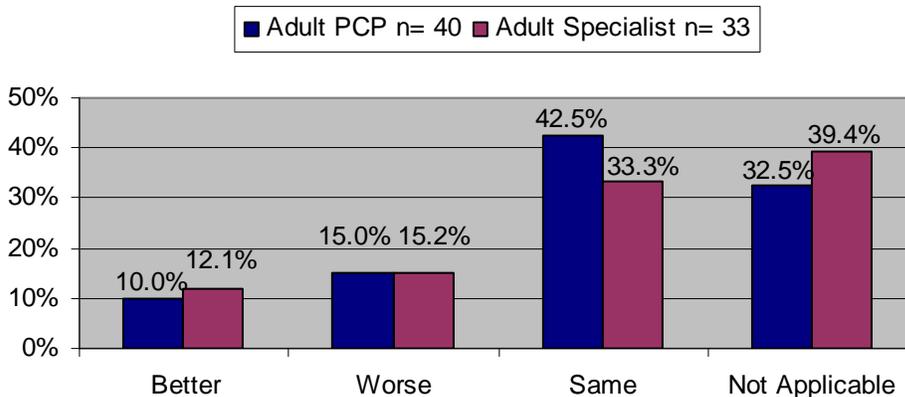
pediatric specialist(s) and 13.5% of former patients reporting that they have a PCP this question was not applicable (Figure 5.31.).

**Figure 5.31. Satisfaction with Pain Management by Pediatric Physicians**



When pain management was compared between adult and pediatric primary care providers, 42.5% of respondents said that it was the same for the pediatric and adult PCP and 15.0% thought that it was worse. Only 10.0% thought that it was better. For the comparison between adult and pediatric specialists, 33.3% of respondents said that it was the same, 15.2% thought that it was worse, and 12.1% said that it was better (Figure 5.32.).

**5.32. Pain Management by Adult Physicians compared to Pediatric Physicians**



## Insurance

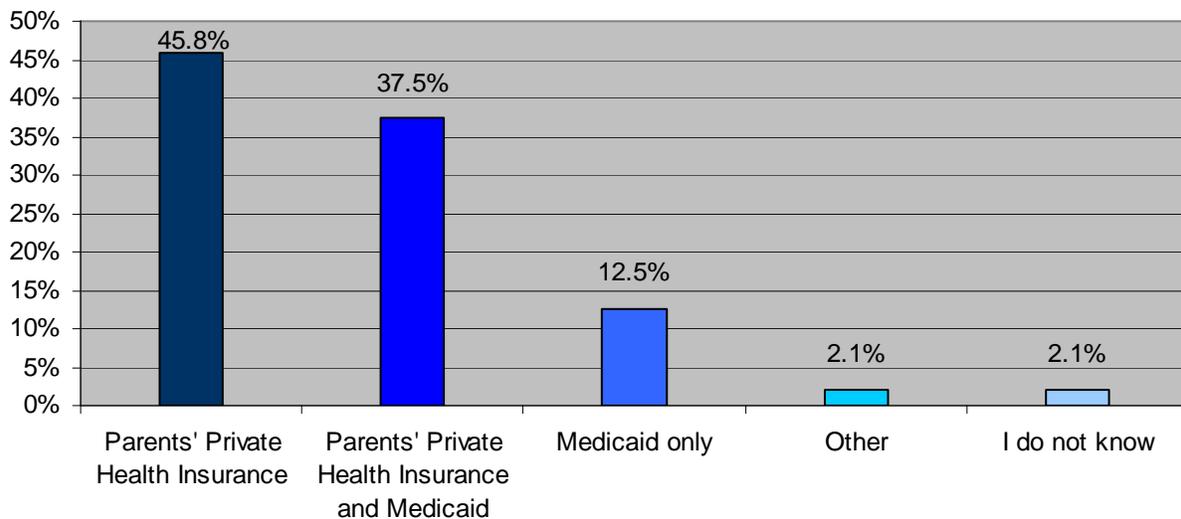
Insurance and health care costs are some of the challenges people report when talking about their transition experience. Many times, insurance coverage and eligibility

for services and equipment change when a patient moves from the pediatric to the adult system (usually between 18 and 21 years of age; sometimes insurances cover patients under their parents' insurance plan up to 25 years of age). These changes pose some specific challenges for patients, such as reduced coverage of treatments, services, or equipment that patients were eligible for through their pediatric health care coverage. The survey looked at patients' pediatric and current coverage and their satisfaction with that coverage. In addition, participants were asked about additional (financial) resources that were available to them as a child and those that are available to them now as adults.

Insurance Coverage

Almost 46% of survey respondents were covered through their parents' private health insurance when they were children (Figure 5.33.). In addition, 37.5% stated that they were insured through a combination of their parents' private insurance and Medicaid, and 12.5% said that they were insured through Medicaid only.

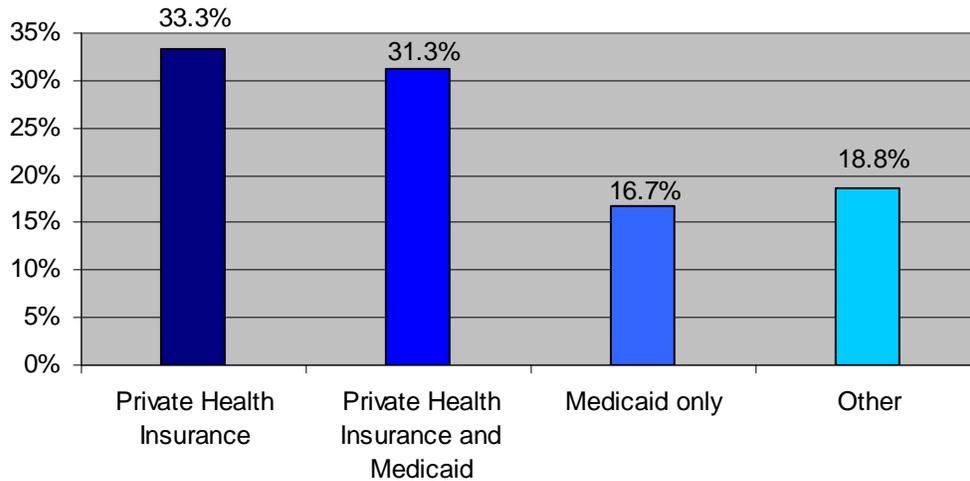
**Figure 5.33. Pediatric Health Care Coverage**



n= 48

As adults, 33.3% are insured through their private health insurance, 31.3% are insured through a combination of private insurance and Medicaid, and 16.7% are insured through Medicaid only (Figure 5.34.). Almost 19% reported that they have another insurance coverage arrangement.

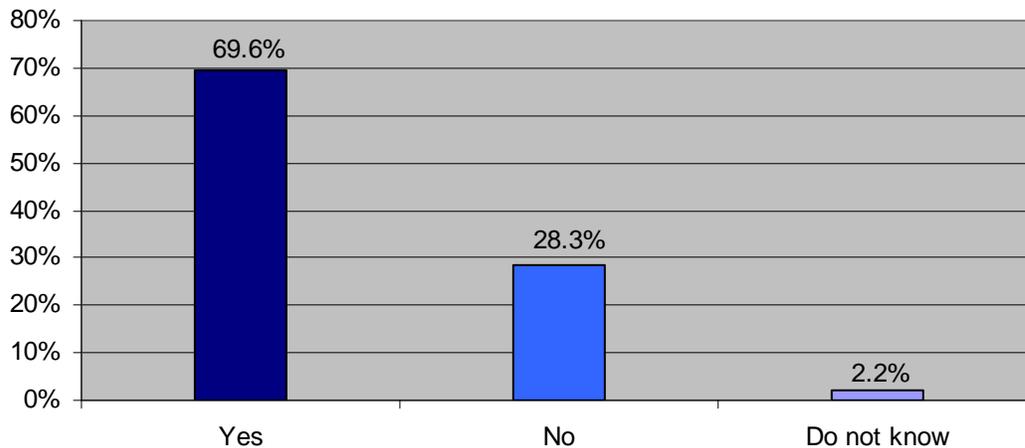
**Figure 5.34. Adult Health Care Coverage**



n= 48

Of all respondents 28.3% stated that they were not satisfied with their current medical coverage and 69.6% reported that they were satisfied with their coverage (Figure 5.35.). A small percentage (2.2%) did not know if they were satisfied or not.

**Figure 5.35. Satisfaction with Adult Health Care Coverage**

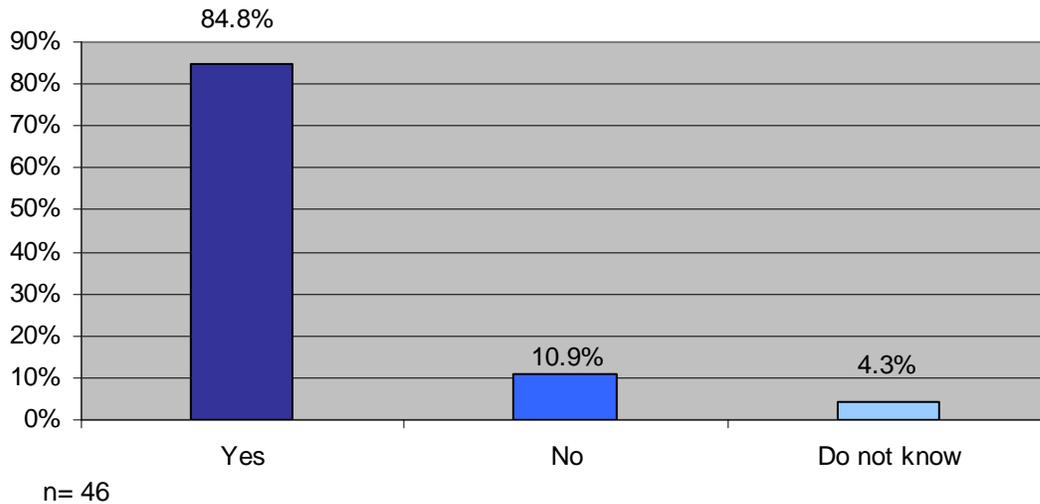


n= 46

**Coverage of Medical Expenses and Medical Equipment**

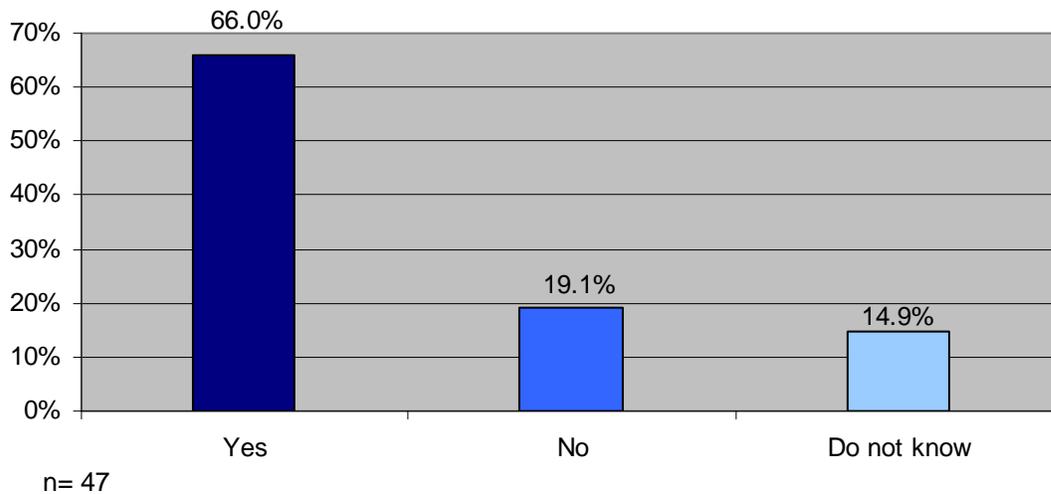
When asked if their medical insurance covered most or all of their medical expenses, 84.8% stated that their insurance covered the cost, 10.9% said that their insurance did not cover most or all of their medical expenses, and 4.3% did not know if their insurance covered most or all of their medical expenses (Figure 5.36.).

**Figure 5.36. Medical Expenses Coverage**



Only 66.0% of survey participants reported that their insurance covered most or all of the medical devices, such as wheelchairs, crutches, glasses, specialized computers, etc. and 19.1% stated that not all of the medical devices they needed were covered (Figure 5.37.).

**Figure 5.37. Medical Equipment Coverage**



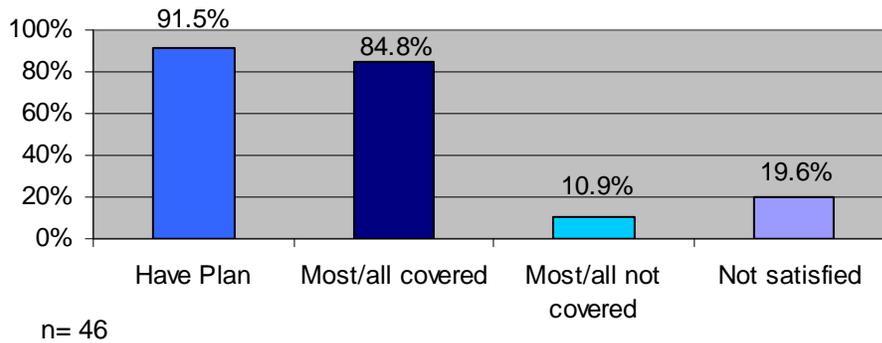
**Prescription Drug Coverage**

In addition to gathering information about participants' general medical insurance coverage the research team was also interested in learning if survey participants had some type of prescription drug coverage and if they did if they were satisfied with it.

A total of 91.5% of survey respondents currently have some type of prescription drug coverage and 84.8% report that their prescription drug plan covers most or all of

their prescription drugs need. Almost 11%, however, reported that their prescription plan did not cover most or all of their prescription drug needs, and almost 20% of respondents stated that they are not satisfied with their current prescription drug plan (Figure 5.38.).

**Figure 5.38. Prescription Drug Coverage**



#### Additional Monetary Resources

Some people who have disabilities or chronic conditions have additional resources that they can tap into to cover their medical bills. Examples of such resources are additional governmental resources, such as Medicare or Supplemental Security Income (SSI) benefits, donations, fundraisers, or trust funds. Two survey questions asked participants what type of additional resources were available to them as pediatric patients and as adult patients. Only very few had access to additional resources. Table 5.1. illustrates how many participants had access to additional resources and what these resources were as pediatric patients and as current adult patients.

**Table 5.1. Additional Monetary Resources**

|                | Resources as Pediatric Patient | Resources as Adult Patient |
|----------------|--------------------------------|----------------------------|
| SSI Benefits   | 11                             |                            |
| SSDI Benefits  |                                | 11                         |
| Drug Discounts | 1                              | 1                          |
| Donations      | 1                              |                            |
| Fundraisers    |                                |                            |
| Trust Fund(s)  | 1                              | 1                          |
| Medicare       |                                | 5                          |
| Medicaid       |                                | 14                         |
| Other          | 8                              | 7                          |

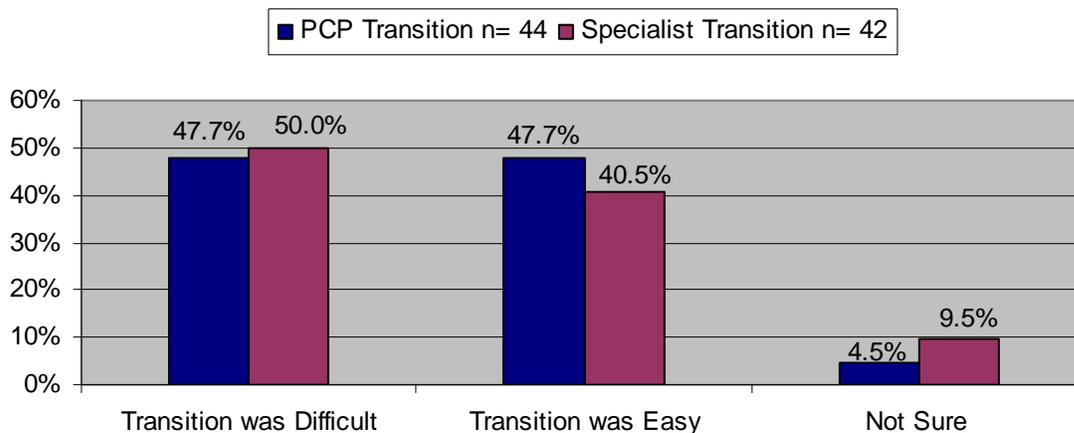
## Move from Pediatric to Adult Health Care System

After a more detailed reflection on various transition topics the research team also wanted to know how former patients or their parents viewed the overall transition from pediatric physicians to adult physicians, which health care system they prefer, and which health insurance plan they like better.

### Transition from Pediatric Physicians to Adult Physicians

Regarding the overall transition from pediatric primary care provider (PCP) to adult PCP, respondents were split into two halves. Exactly 47.7% of respondents felt that the transition had been easy and 47.7% felt that the transition had been difficult (Figure 5.39.). For the transition from pediatric specialist to adult specialist 40.5.0% felt that the transition had been easy and 50.0% felt that it had been difficult. Almost 10% were not sure if the transition had been difficult or easy (Figure 5.39).

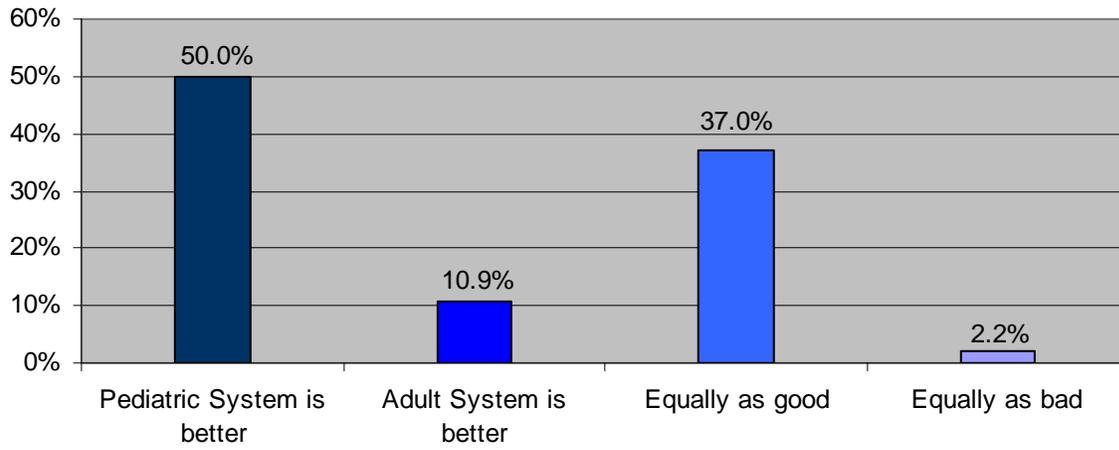
**Figure 5.39. Overall Transition Experience**



### Preference of Health Care System

When asked which health care system was/is better in providing services to patients, 50.0% of respondents reported that the pediatric health care system is better, 37.0% said that the pediatric and adult health care systems are equally as good, and almost 11% felt that the adult health care system is better (Figure 5.40.).

**Figure 5.40. Preference of Health Care System**

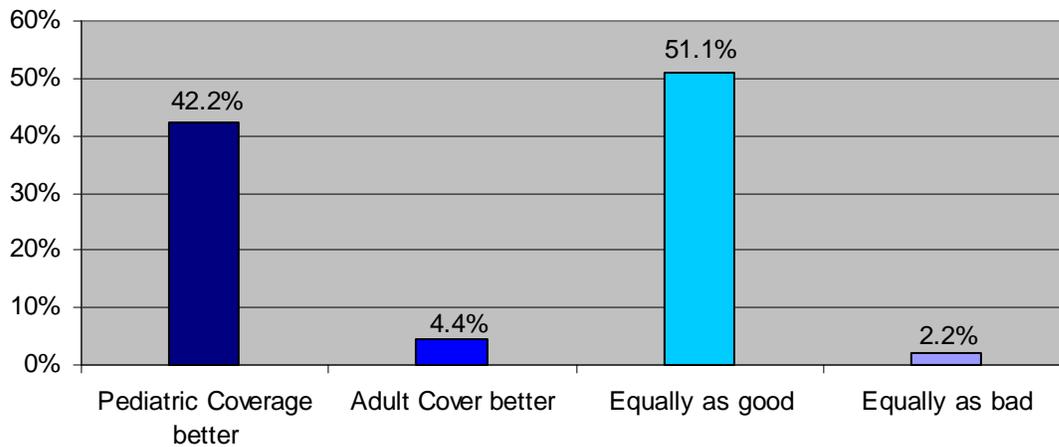


n= 46

Preference of Insurance Coverage

Survey participants were also asked which insurance coverage they felt provided better coverage for them; the current coverage plan they have as adults or the pediatric plan that they had as pediatric patients. Interestingly, 51.1% of participants reported that the pediatric and adult health insurance plans are equally as good, followed by 42.2% of respondents who said that the pediatric insurance plan was better. A small number (4.4%) stated that their adult health insurance plan is better (Figure 5.41.).

**Figure 5.41. Preference of Health Insurance Coverage**



n= 45

## SECTION 6: FINDINGS OF FOCUS GROUP SESSIONS

Phase III, the focus group sessions, were held to learn more about a) patients' experiences with the transition from the pediatric to the adult health care system and b) patients' recommendations for improving the transition process. The seven focus group participants of the two focus group sessions were asked about their experiences with the overall transition process, their doctors' collaboration with colleagues and patients, and insurance coverage. In addition, participants were asked to identify any other topics they deemed important regarding their transition experiences.

### Patients' Experiences with the Transition Process

During the focus group sessions, participants were first asked about their experiences with the transition process. Areas that were addressed included: a) the general transition process, b) physician services, and c) insurance coverage. In addition, participants mentioned legal issues, availability of medical records, transportation, and advocacy as other areas of concern.

#### General Transition Process

Focus group participants mentioned four different areas that were difficult in their transition process. First, some of the focus group participants felt that once they reached transition age (18 to 21 years of age) they were **dropped from services** immediately. As one participant stated, "And I felt like after 18, I became invisible and there is really nowhere else to go." Similarly, some of the participating parents felt that transition into adult services cannot be initiated by reaching transition age alone. For some patients who have had long-term medical conditions, medical procedures fall right in the time period of their transition age. In these cases, parents argued, transition should be delayed until medical procedures (e.g. surgeries, treatments) have been completed. As one mother put it:

I just think that there can't be a cutoff right on that date, 'we can't see you anymore.' I don't see how you can be that...how can you just cut it off on that date, it doesn't make sense. I know that all of our kids have things that are going to continue to go, but this was an emergent problem he had .... Why couldn't they have figured out a way around it to take care of this kid, who had been there all of his life? He wasn't a new patient to any of these doctors. This doctor had watched him grow and go through everything and then he just couldn't help him. ...they need to make that adjustment...

Another issue focus group participants mentioned was that they were **not prepared for their transition** and did not know where to turn to for their next steps in the adult health care system. One of the participating former patients stated that her "mother went looking outside of the hospital for specialists, and there was absolutely no direction at all." All participants were in agreement that more and better transition preparation is needed for transitioning patients.

Third, focus group participants reflected on the differences between the pediatric health care system and the adult health care system. For many, the **adult system seems to be more difficult to manage than the pediatric system**. For one, new physicians have no background information on their patients. For many patients who received most or all their services at Alfred I duPont Hospital for Children (AIDHC) this is a new experience. One of the parents said that “when you transition, your new doctors have no basis to give you anything for a while. It takes them a long time until they know your child the way they did in the pediatric world. It’s hard.” One major complaint stated by many focus group participants is that adult specialists do not have the holistic view that pediatric specialists have and that they do not work together with other physicians. One former patient spoke for many other participants when she reflected on her experience with adult physicians:

The regular outside doctor doesn’t give a [expletive]. He just doesn’t care. Well some of them do. But the majority of them don’t. Especially in the adult world, it is all about their specialty. They don’t see how it interacts with the other things that are going on in the body and that is a big difference there. At least at AI you had the specialty but they knew it would be okay if they were working with something else. They weren’t afraid to talk to each other. In the adult world, they don’t want to talk to the pediatric world. You had some luck getting the pediatric world reach out to the adult world, but whenever I have suggested that they go back to someone who could give them a better understanding of his position they won’t. They never did. They just don’t want to take on the little something extra that it is going to take to handle a young adult who’s progressing and whose body is deteriorating quickly.

A fourth area of concern of the focus group participants was the **physicians’ lack of knowledge about pediatric conditions previously considered fatal that many patients now survive into their adult years**. Participants were very aware of the fact that there is not enough knowledge out there yet about some conditions and that adult physicians do not necessarily know how to treat these pediatric conditions. One mother of a young adult daughter addressed the other young adults in the focus group sessions and said:

You as adults, 20 or 30 years ago, were not alive. There were no interventions in place for you. I don’t think they know what to know, what to do with people like you and people like my daughter. I think that we lack research. Research of these people, what is working for them, what did we do right when we did these surgeries and what didn’t work, what should have not been done.

In response to this statement one of the young adults attending the meeting stated that she wished the focus was on preventing further degeneration of her condition rather than waiting until she degenerates:

Congenital disorders that are not progressing have been around for the past 30 years, and there have been no changes, but the life expectancy and the cognitive

abilities of patients that have these disorders has drastically changed and I think they need to move the focus of 'let's wait for them to degenerate and need surgery until we do anything' cause I think that a lot of it is preventable.... I think if they focused on what ...to do...things would be a lot better.

### Physician Services

Focus group participants talked about their relationships with pediatric and adult primary care providers (PCPs) and specialists as well as collaboration between their pediatric and adult physicians during the focus group sessions. Regarding the transition process from pediatric to adult PCP, participants reported that **transition went smoothly** in cases in which the **transition process** had **started early** and **physicians communicated** with one another. One participant stated:

I had a pediatric doctor who is very supportive, has always been supportive....He and I actually started two years before we knew 21 [years] was coming...It was really through the nurses at AI [hospital] who said they had a [adult] physician who had really impressed us. So I took the name to my [pediatric] physician and he said 'Why didn't I think of him?' So they connected, even though his practice was almost closed at that point. He has been my best support.

Another participant talked about the importance of good communication between the pediatric and adult physician: "This is what happened between my pediatrician to my [adult] general practitioner, the good communication ahead of time. They talked so it did make the transition smooth." In contrast, failure to communicate made the transition process more difficult: "And there was no communication between my family doctor and AI [hospital] and he [family practitioner] had to beg to get partial records sent over from AI duPont."

As for specialist services, participants mentioned three areas that were challenging in their transition process. First, it was very difficult for some patients to **find adult specialists that could or would treat their conditions**. For former patients who had various specialists take care of them during their childhood years, it was very difficult to replace all of them once the patient reached adulthood. One mother reported that her "son was seeing six specialists and to this day I have not been able to find replacements for all of them, four years later." Even when pediatric specialists tried to help identify adult specialists they were not always successful: "I have my pediatric orthopedist looking for an [adult] orthopedic doctor. He is very willing to talk to people on the phone but he just can't find anyone." An additional challenge that some focus group participants mentioned was that their adult specialists do not communicate with one another, which makes it difficult to receive appropriate treatment. Similarly, some participants who had multiple medical conditions were concerned about the specific focus of specialists on only one medical condition rather than taking a more holistic approach and seeing medical conditions as being interrelated. One former pediatric patient said: "...they are not looking at how the issues are all connected. They are just looking at the one problem and that was one of my biggest fights with my doctors, was that they need to look at all of the problems together, not just one because they are all

connected". Second, according to focus group participants, **adult specialists do not take as much time to get to know the patient**, understand the medical condition, and develop a treatment plan as pediatric specialists at AIDHC did. One of the former patients put it this way: "...you are just not used to a doctor taking 10 minutes to look at you and decide what is going to work best. You are used to being there for hours and seeing the doctor multiple times." Some of the focus group participants were frustrated about adult specialists' assumptions about their medical conditions and abilities. One of the former patients expressed her frustration this way:

It is kind of like being put on an alien planet. Nobody knows what to do with you, and they have preconceived notions about how conditions like you have accompanied problems, such as cognitive issues. They assume that there is something going on and they just want to talk to your parents instead of you.

Finally, as mentioned earlier, focus group participants talked about how **adult specialists do not know how to treat patients with pediatric conditions** that now live into adulthood. Various focus group participants described similar situations, all referring to adult specialists not knowing how to treat pediatric conditions. As an example of participants' experiences:

The medical world just isn't ready for these children with complex disabilities because they haven't been trained for it; they haven't had to deal with it... You can't blame just AI, and you can't blame the person that you are trying to see, you have to go all the way back to day number one in their medical training because they just haven't had the population to deal with. It is tough, it is going to be really hard to turn it around... There are some things that are just so common in pediatrics, but for an adult [physician], it is just never seen. It is really hard. I don't know how we are going to get the adult world to understand that we need individual attention. First you have to get through the guard, that 'I know it all.'

When looking at transition processes from pediatric to adult specialists that went well, focus group participants mentioned, just as they did for the transition to adult PCP, that **communication and collaboration helped make the process easier**. One mother shared her experience with the pediatric orthopedic specialist that had treated her son for many years: "I think the strong point was that my son was going to need surgery quickly after he turned 21, so the surgeon at AI recommended who to go to for the surgery and actually talked to him on the phone and coordinated getting the x-rays over, coordinated getting the data, what he should do in the surgery and what he shouldn't. So that was very helpful for that specific part of the transition..."

#### Insurance Coverage

For all focus group participants changes in insurance coverage after transition from the pediatric to the adult health care system were challenging. Issues reported were either related to **reduction of coverage for medical equipment, treatments, and therapies or denied coverage** for physician services. Participants provided many examples of reduced coverage. These reductions were not only true for

Medicare/Medicaid coverage but also for private insurance. One example a participant provided was the reduced coverage for medical equipment she needs:

As a child Medicaid was my primary insurance and I had coverage for everything. The problem that I have as an adult is that almost nothing is covered. Medicare will not pay for anything. My wheelchair wasn't even covered, and that alone is \$17,000...As an adult, Medicare is your primary insurance, and they cover 20%, and if Medicare denies it, it goes over to Medicaid, and they normally won't cover it.

In addition to reduced coverage, insurance coverage may also deny treatments that physicians and therapists think is necessary for their patients. As one focus group participant stated: "A lot of times, you will find that your doctor, your therapist, and yourself deem something medically necessary. When it is submitted to Medicaid they will deny it because they won't deem it necessary. They won't approve it, they won't pay." Some focus group participants reported that their pediatric doctors and their children's teachers made them aware of the reduced coverage in adult health insurance and helped them receive needed medical equipment before the child transitioned from pediatric insurance coverage to adult coverage:

...we are fortunate being at the [name] school. They were very progressive and proactive about it in making sure that you get everything. Even if you think you have one more year in a wheelchair, not to get it after the twenty-first year. Any adaptive equipment they strongly suggested getting before you leave there.

One main concern focus group participants shared was **that insurance coverage only covers therapies if they see improvements in a patient's condition**. If a patient reaches a plateau coverage may be terminated. In addition, often insurances have caps on therapy sessions, meaning that only so many treatments or therapy sessions are covered regardless of the outcome of treatment. As one participant put it: "Once you reach a plateau you are in trouble. Everything is just over. They are going to wait for you to degenerate before they consider continuation of service. It's like two steps forward and one step back."

Another challenge participants experienced with their adult coverage is that some **specialists and out-of-state specialists are not covered** under their insurance plan. For example, one participant who has Cerebral Palsy sprained her ankle and needed specialized physical therapy. As she reported, "My doctor recommended that I go to Baltimore because they specialize in PT. But the insurance wouldn't cover it so I had to cancel the appointment." One other former patient stated that she "can't go out of state. Well, I could if I wanted to pay out-of-pocket, but my insurance won't let me go out of state." Finally, another participant reported on the difference between her pediatric coverage and her adult coverage:

When I went to AI [hospital] and had surgeries as a child I was completely covered under my mother's insurance. It was with an HMO and even though it

was out-of-state...we did not have any problems with getting them to pay for anything...It is my own personal insurance so I don't have to work with Medicare or Medicaid but it is sometimes difficult because some doctors don't participate with my insurance, meaning that they don't want to accept what my insurance company wants to pay, so I often have to pay fees out-of-pocket.

While focus group participants were satisfied with their pediatric coverage adult insurance coverage seemed to be more challenging. Main concerns were the reduced coverage of equipment and services and the difficulties receiving coverage in general. According to focus group participants' reports, adult insurance coverage makes the transition process more difficult in that patients lose some of the benefits they received as pediatric patients.

#### Additional Challenges

In addition to the areas covered by the focus group protocol, focus group participants mentioned other challenges as well. Some participants had a **difficult time receiving medical records** from their pediatric physicians. One participant reported that she had, "...called and written letters. In order to get some x-rays that we needed, I had an appointment to go and pick up the specific x-rays and when my son got there they wouldn't give them to him because they said they were giving it to him next week, not this week." Another participant reported that her "primary care physician only has my partial records. She doesn't have my full records and I have never been able to find out what the problem was."

Another challenging area that some participants mentioned **was transportation to doctors' offices**. For some, transportation is not available and for others transportation puts a strain on their fragile health if they have to travel far. One attendant said that "transportation is also a huge issue. An eight-hour day turns into a 12-hour day and there is no time for therapy or anything else so you regress" and another person stated that "transportation has been a huge issue for me. It can sometimes take hours to see my specialists."

Focus group participants acknowledged that pediatric physicians' hands are tied when it comes to treating them as adults and that they are the ones who have to advocate for themselves. One participant reported on the legal limitations that physicians at AIDHC have regarding their former patients:

I have just found that no matter how much the doctors want to treat you; their hands are tied because they are operating under a trust fund. My doctor has said that he would have loved to perform my surgery and to continue to treat me, but he can't, he can't legally.

Focus group attendees were in agreement that it was up to them to change the transition process and to advocate for more collaboration between pediatric and adult physicians. They saw a willingness of their pediatric physicians to work with adult

colleagues. One participant summed it up when she acknowledged that “AI [hospital] really want to do this, I just think that more people need to speak up...”

## **Recommendations for the Improvement of the Transition Process**

During the focus group sessions participants were asked how the transition process could be improved. Many suggestions were given by participants. These suggestions could be divided into five categories: a) transition coordination, b) resources, c) communication, d) insurance, and e) research.

### **Transition Coordination**

Focus group attendees began by talking about different ideas for the improvement of the transition process. Very early in the discussion, participants of both focus groups came up with the idea of a “**transition team.**” As the discussion continued participants became more and more detailed about what the team should look like, where it should be located, who should be on such a team and what their roles would be. Participants felt that a transition team should consist of a social worker specializing in transition, other transition specialists, parents, physicians, a records specialist, and an insurance specialist. The team would be led by a transition coordinator and located at AI duPont Hospital. The transition process should start early, two to four years before the transition. Many ideas were shared and one example is the following quote:

I think there needs to be a team that is coming out of AI that starts about two years before that calls and tells you that you are going to have a meeting with the Transition Team and you are going to meet every three months or six months so that everything can be brought together to get you out into the adult world.

In addition to a transition team, focus group participants were also interested in **guidance** about the steps they will have to take and what patients’ options are once they transition out. As one participant put it, “I think that patients need to be provided with all of the options, where they can go for specialized services, for another primary care [provider], for anything that could possibly be necessary; because I have had to do it all on my own.”

### **Resources**

In addition to a transition coordination team, the focus group participants suggested that physicians and social/case workers at the hospital provide various resources to families and patients who are beginning the transition process. Desired resources were **lists of adult primary care providers and specialists** in the geographic area that provide services to young adults with chronic medical conditions and/or disabilities and **discharge summary forms** that outline the transitioning patients’ diagnosis/diagnoses, medical history, medications, and needs. The idea was to receive a short patient discharge form that patients and their families could take with them to a new adult health care provider to give him/her a history on the patient. For many focus

group participants a list of available PCPs and specialists seemed very important and useful:

I think that the hospital really does need to compile lists of potential doctors. While the doctors might not know, more just needs to be done. They need to sit down with patients and even contact former patients to see who they are going to...they just need to put forth some effort.

Focus group participants agreed that a discharge summary form would be helpful in the transition process. In particular it would provide accurate information about a patient's conditions that a new provider could use as a starting point:

...it could be a summary from each of you [them] as you are leaving. If you have been with them for twenty one years, then yes do a 21 year summary, it can't be that hard to do. Because all they have to do is list your operations, list the results of it, list the complications you had and then a summary at the end. If you put all that together then at least you have a backpack to take with you.

### Communication

Communication was another area that focus group participants felt needed improvement. Attendants recommended that a) adult and pediatric physicians reach out to one another and communicate and b) that adult physicians listen to parents and respect them as experts that know their children best.

In both focus group sessions there was a lively discussion about the need for **improved communication between physicians**. It was recommended that both sides, the pediatric and adult health care systems, open up and communicate with one another. One desire was for "the adult world to reach out and call the pediatric world" and another one was that pediatric physicians at Al du Pont Hospital "should at least be able to do the training for the outside [adult] doctors." In addition, participants wanted Al duPont Hospital to collaborate more with their adult colleagues:

If they would break down the walls a little bit and be able to interact with the adult world. Now the question becomes what do they do with all the people from all the different states. That invitation could go to them. Whether they want to participate in it, they don't have control over, but at least put an invitation out there. 'Look we have dealt with these people possibly up to 21 years, would you like to know how we have done it?' Would this ever happen? It's a dream, I do not know. But just from an educational purpose to just see 'Look this is what happens [in the pediatric setting]'

Another mentioned area for improvement was the **communication between parents** of adult children with limited cognitive abilities and **adult physicians**. Parents felt very strongly about physicians listening to them rather than assuming they know everything about their patient. One mother summarized it when she stated, "Just honor

that we know our child. Just honor that we have been through it all with them and we know them better than anyone else. They should respect that and I just feel that it isn't. "

### Insurance Coverage

Besides the many challenges participants reported with the transition from pediatric to adult health care coverage, one participant also had a recommendation for improving insurance coverage. "...all they are looking at is what kind of money they have right now. I really think that if they look at the whole picture...they don't think about how the decision they are making now will affect you for the rest of your life." This young woman's argument was that if insurances **covered the immediate treatments**, therapies, and equipment they might actually **save money in the long run**. This way both the patient and insurance company would benefit.

### Research

One of the participating mothers repeatedly mentioned the need for **more research on pediatric conditions in young adults**. Even though she was the only one talking about research, all other participants were in agreement that more needed to be done for young adults with pediatric conditions that survive into their adult years. She felt that "there is need for research out there on this population because you can't change without research and I don't think there is research. It is a major problem." With more research and developing knowledge young adults transitioning from pediatric to adult health care services could receive better health care.

## SECTION 7: RECOMMENDATIONS

The following recommendations are based on the information collected in all three phases of this project. These recommendations may be helpful in guiding the next steps for improved transition processes from pediatric to adult health care services.

- 1. Conduct another survey about the transition process with a larger, more diverse sample.** The sample sizes for the three phases of this project were small and findings from this pilot project provide only a first insight into the transition experiences of young adults and their families. An extended survey conducted in single stage with a larger, more diverse sample is needed to better understand the transition experiences and needs of young adults and their families. This survey could be conducted by AIDHC or the Office of Children with Special Health Care Needs of the Delaware Division of Public Health.
- 2. Explore existing adult community services for individuals with medical conditions and disabilities for gaps in service delivery.** Findings from the extended survey showed that a large minority of respondents were not aware of the adult community rehabilitation and day programs and mental health services that were available to them. It is not known if this finding reflects actual gaps in services or in respondents' lack information about available services; therefore, this issue needs to be explored in more detail. If services are available and individuals do not know about them, more information needs to be provided to transitioning youth and their families about existing resources in the community. If services are not available, a plan needs to be developed and implemented to address service gaps. This issue should be explored by the Office of Children with Special Health Care Needs of the Delaware Division of Public Health.
- 3. Educate adult health care providers on the needs of transitioning youth and their families.** One of the difficulties young adults and their families faced in the transition process were the different approaches adult health care providers took in providing services to patients. It might be helpful to educate adult primary care providers and specialists on the differences between the pediatric and adult health care setting and the needs and expectations young adults and their families have. This may raise providers' understanding of transitioning patients and help them reflect on (or adjust) their treatment of patients. Information could be provided via email newsletters, on websites frequented by medical health care providers or as part of professional presentations, such as hospital grand rounds.
- 4. Begin the process of exploring collaborative efforts between pediatric and adult physicians.** One of the main challenges project participants pointed out was the lack of communication and collaboration between

pediatric and adult physicians. Committees such as the Alfred I duPont Hospital for Children Transition Committee need to begin the process of talking to adult colleagues from hospitals such as Christiana Care, rehabilitation facilities such as Moss and Magee, and regional primary care providers and specialists about collaborative efforts in supporting patients in their transition from pediatric to adult health care. Pediatric and adult physicians could explore existing collaboration models and develop and implement a plan for improved communication.

- 5. Begin the process of exploring ways to provide needed transition resources to families and patients who are in the transition process.** Respondents from Phases II and III provided multiple data about their need for resources. Resources needed are a) help with identifying adult primary care providers and specialists and b) transition process information. The AIDHC Transition Committee should collaborate with existing state and community organizations, such as the Office of Children with Special Health Care Needs of the Delaware Division of Public Health, Christiana Care Health System (CCHS), the Medical Society of Delaware, the Delaware Coordinating Council for Children with Disabilities, KenCrest Services, the Center for Disabilities Studies at the University of Delaware, and other surrounding states' organizations on developing and disseminating information brochures and websites that address such needs as finding adult physicians and providing guidance in and for the transition process. Existing resources could be identified, modified, and publicized so young adults in transition have access to and know where to find useful information.
- 6. Begin exploring the development of a transition coordination team that assists families and patients in their transition from the pediatric to the adult health care setting.** Results from Phase III of this project indicate that there is a need for a formalized transition coordination process for young adults and their families throughout their transition process. The AIDHC Transition Committee needs to develop a plan for a transition coordination process, identify who could and should benefit from such a process, address how the plan could be implemented, and address how it could be financed. Collaboration with other state and community organizations would be helpful in planning for such a process.
- 7. Work to address existing health insurance coverage shortcomings and seek a dialogue with health insurance providers.** As findings from this pilot project showed, a large number of individuals experience a significant reduction in coverage for treatments, therapies, and equipment once they transition from pediatric health coverage to adult health coverage. The AIDHC Transition Committee, in collaboration with other state and community agencies, such as the Office of Children with Special Health Care Needs of the Delaware Division of Public Health, Christiana Care Health Systems, Easter Seals, etc. should outline the current difficulties with insurance

coverage and seek out private and public health insurance companies, such as Blue Cross Blue Shield of Delaware, Aetna, Coventry, and the Division of Medicaid and Medical Assistance at the Delaware Department Health and Social Services, to discuss current insurance policies and develop a plan of action on how to improve coverage for young adults with various health care needs.

## SECTION 8: CONCLUSION

Information from this pilot project 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 system. Findings indicate that the majority of respondents have access to a primary care provider as well as health care specialists. However, a large minority of participants experienced challenges in accessing care, such as not being able to identify primary care providers and specialists and having transportation difficulties in getting to health care providers. In addition, other reasons prevented participants from accessing physicians. These other reasons need more exploration to gain a more complete picture about the challenges young adults and their families face in the transition process.

Overall, respondents reported being satisfied with the health care they receive from their physicians and specialists in the adult health care system. However, satisfaction dropped slightly when compared to their satisfaction with the pediatric care they received. In addition, besides being satisfied overall, participants pointed out some challenges that they faced in their transition to adult health care providers. Almost half of all extended survey respondents reported that their transition was difficult. Difficulties included finding adult health care providers, adult health providers not taking a holistic approach to treating patients, lack collaboration between pediatric and adult providers, and improving health care coverage of needed treatments and equipment.

According to project participants, all have access to general care in their communities and many use these services. More than three quarters reported that therapeutic services are available to them in their communities if they need them, and a quarter makes use of these services. However, availability of mental health services and private duty home health care was only reported by a small majority, and availability of services dropped further for community rehabilitation and day programs. Further exploration is needed to determine why these services are not available in some communities, if and how much these services are needed, and how they can be made available to young adults who transitioned into the adult health care system.

Recommendations provided by focus group participants indicate that there is still much to do to improve the overall transition experience of transitioning patients and their families. Patients who transition and their families do not seem to get the information they desire regarding the transition process. In addition, they do not seem to be well prepared for the transition experience into the adult health care system. Based on this information, changes need to be made to the existing transition process so young adults and their families will be able to experience a smooth transition from the pediatric to the adult health care system.

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## APPENDICES

**Appendix A:**  
**List of “Other” Conditions as Indicated by Participants of the Postcard Survey**

| Condition  | Number of Participants who indicated that They had this Condition |
|--|---|
| 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   |
| <b>Total number in category “Other Conditions”</b> | <b>65</b>   |

**Appendix B:  
List of “Other” Conditions as Indicated by Participants of the Extended Survey**

| Condition                             | Number of Patients indicating this Condition |
|---------------------------------------|--|
| Arthritis                             | 1  |
| Biliary Atresia                       | 1  |
| Bipolar Disorder                      | 1  |
| Charcot Marie Tooth Disease           | 1  |
| Chronic Obstructive Pulmonary Disease | 1  |
| Congenital Birth Defects              | 1  |
| Epilepsy                              | 1  |
| Hemochromatosis                       | 1  |
| Hydrocephalus                         | 1  |
| Hypothyroidism                        | 1  |
| Large Granula Lymphocytic Leukemia    | 1  |
| Legg Calvette Perthese Disease        | 1  |
| Mental Retardation                    | 1  |
| Morquio Syndrome                      | 1  |
| Neurodegenerative-undiagnosed         | 1  |
| Neurofibromatosis                     | 1  |
| Neurgenic Bladder                     | 1  |
| Rett Syndrome                         | 1  |
| Scleroderma                           | 1  |
| Scoliosis                             | 5  |
| Traumatic Brain Injury                | 1  |
| Tuberous Sclerosis                    | 1  |

**Appendix C:  
List of Specialists Currently Seen by Former Patients as Described by Survey  
Participants**

| Specialist         | Number of Patients seeing Specialist |
|--------------------|--------------------------------------|
| Endocrinologist    | 2                                    |
| Gastroenterologist | 7                                    |
| Hematologist       | 3                                    |
| Nephrologist       | 4                                    |
| Neurologist        | 7                                    |
| Neurosurgeon       | 3                                    |
| Ophthalmologist    | 1                                    |
| Orthopedic Surgeon | 2                                    |
| Orthopedist        | 1                                    |
| Pain Specialist    | 1                                    |
| Psychiatrist       | 2                                    |
| Psychologist       | 1                                    |
| Pulmonologist      | 4                                    |
| Rheumatologist     | 1                                    |
| Spine Specialist   | 1                                    |
| Urologist          | 4                                    |