



# Transition

## from Pediatrics to Adult Medical Systems for Young Adults with Disabilities or Special Health Care Needs

April 2014



This project is supported by a grant from the FISA Foundation

**ACHIEVA** is southwestern Pennsylvania's largest provider of comprehensive services and supports for people with disabilities and their families. ACHIEVA serves more than 14,600 individuals with disabilities and their families and is the only agency of its type in southwestern Pennsylvania that provides lifelong supports. From early intervention therapies for infants to in-home support for medically fragile senior citizens, ACHIEVA provides a full spectrum of services for people of all ages and abilities and their families.

**ACHIEVA's Disability Healthcare Initiative** is providing statewide leadership on improving access to health care for individuals with disabilities through education, public policy and advocacy. We work to increase physical and programmatic access, medical workforce development and education. ACHIEVA works with many stakeholders, including individuals with disabilities and their families, medical professionals, hospitals and health centers, government agencies, educators, insurance companies, foundations and disability advocates to develop viable solutions to increase access to physical health care and dental care for people with disabilities.

In 2007, ACHIEVA's Disability Healthcare Initiative wrote *Access to Oral Health Care for Pennsylvanians with Disabilities: A Rising Public Health Issue* which identified the issues that contributed to oral health care for people with disabilities being a serious public health problem. Among the issues are lack of dental provider preparedness and lack of Medicaid and private health insurance for adult dental care.

In 2009, ACHIEVA continued to pursue this issue by writing *Access to Dental Care for People with Disabilities: Challenges and Solutions — A Report to Pennsylvania's Legislators*. This report developed seven recommendations including directing the Legislative Budget and Finance Committee to study and issue a report on the disparities in dental care for Pennsylvanians with disabilities. A resolution has been introduced in the state legislature each of the last two sessions, with ACHIEVA's support, but one has not yet passed.

In 2012, ACHIEVA continued the nationally recognized work of the FISA Foundation on increasing access to health care for women with disabilities and wrote *Access to Healthcare for Women and Girls with Disabilities: A Report to Pennsylvania's Legislators*. This report also developed seven recommendations including instituting a part-time loan forgiveness program, using existing funding, for medical and dental professionals. A member of the Pennsylvania legislature has stated his intent to introduce this legislation.

In addition to these reports, **ACHIEVA's Disability Healthcare Initiative** created a website in 2013 on health care for people with disabilities ([www.personfirsthealth.org](http://www.personfirsthealth.org)) that features a broad range of information and resources, developed a series of webinars on access to health care and continues to educate key policymakers on these issues.

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## THE PROBLEM

Currently in the United States, there are approximately 10.2 million people with special health care needs (SHCN) under 19 years of age.<sup>1</sup> Each year, 750,000 adolescents with SHCN cross into adulthood.<sup>2</sup> Health care transition — the process of moving from pediatric medicine to adult-oriented medicine — is a necessary process for these youth.<sup>3</sup> Transition can be difficult when a child with complex, chronic needs has been cared for by the same pediatric team for many years, especially when the team may have been credited with saving the child's life and supporting the family through very difficult moments.

In the 2001 National Survey of Children with Special Health Care Needs, among adolescents ages 14 through 17, only 15 percent of 5,400 interviewees reported receiving appropriate guidance and support in health care transition, indicating that health care transition is stressful for young people and their families and that the health care system is not adequately prepared to offer effective and efficient transitions.

## THE SOLUTIONS

In an effort to improve health care transition for adolescents and young adults with disabilities and special health care needs:

**Medicaid must remain affordable and comprehensive for adults with disabilities.** Access should not be limited by work requirements or fees, as outlined in Healthy PA, which may restrict coverage for those with disabilities.

**The Pennsylvania Legislature should pass legislation to establish a part time Primary Health Care Practitioner Loan Repayment Program** through the Department of Health, using existing funds, as an incentive to recruit and retain practitioners to serve people with disabilities and other Medicaid recipients, especially in Pennsylvania's underserved areas.

**The Pennsylvania Department of Education should ensure that an Individualized Health Plan is a component of the Individual Education Plan or 504 Service Agreement** for students with disabilities or special health care needs.

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs, should ensure that Medicaid Managed Care Organizations and providers are aware of and in compliance with the requirements of the Operations Memorandum, effective since 2009.**

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs, should establish and promote Medicaid billing codes** which allow physicians to bill for the extra time it takes to serve individuals with complex needs.

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs should urge all Medicaid Managed Care Plans to work with their physicians and physician groups to develop more adult and pediatric medical homes** for people with disabilities and special health care needs.

**Medical schools in Pennsylvania need to continue to include education about health care transition for youth with disabilities and special health care needs** as part of the didactic and clinical training for medical professionals.

## TRANSITION: A TIME OF EXTRAORDINARY CHANGE

The transition from pediatric to adult health care coincides with the transition to adulthood. During this stage of development, adolescents and young adults experience leaving high school, starting work, attending a vocational school or college, joining a branch of the military, living away from the parental home, setting up an independent home, dating, and for some, finding a spouse or partner and eventually beginning a family. This stage also involves accepting more responsibility for oneself, making independent decisions and becoming financially independent. For young adults with and without disabilities, it is a time of extraordinary changes, both for the young adult and his or her family.

Many young adults with disabilities and special health care needs may not pursue post-secondary education, live independently or have a spouse, partner or family of their own. Many young adults with disabilities are not able to make decisions without assistance or to become financially independent. Whatever degree of independence they do achieve will require more planning, more support from their families and more involvement with social service systems. For their parents, it may be the first time they confront the need for long-term planning and lifelong supports.

## YOUTH WITH DISABILITIES OR SPECIAL HEALTH CARE NEEDS

The Maternal and Child Health Bureau defines children with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>4</sup>

Blum, Hirsch, Kastler, Quant, and Sandler<sup>5</sup> define health care transition as “a dynamic, lifelong process that seeks to meet [a young person’s] individual needs as they move from childhood to adulthood” and assert that “the goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”

Young people with disabilities and chronic health conditions and their families described the transition from pediatric care to adult-oriented care as distinctly negative and indicative of the level of trust that young people and their families experienced with pediatric providers but not with adult-oriented providers.<sup>5,6</sup>

**“We forget that individuals with disabilities need preventative health care like the rest of us. I think we tend to think that because of their disabilities, routine care is not necessary and that is the wrong approach. Had my daughter not read about breast health and self-care in a magazine, she would not have discovered a lump in her breast. She spoke up and asked about further testing which in turn meant successful treatment for breast cancer. We, as parents, have to listen to our kids and what they need but we also have to realize that they need to be given the skills to know themselves and advocate for their own health care,” Linda, parent of a young adult.**

# STAKEHOLDER AND SURVEY RESPONSE

## Stakeholder Responses

In 2013, ACHIEVA's Disability Healthcare Initiative staff convened a stakeholder group of families of people with disabilities and special health care needs, health insurers and physicians as a way to better understand the issues around health care transition.

### Family Concerns

Families expressed concerns about the stress of providing care to their family member while managing work and other responsibilities. Families also stated that they are worried about their child turning 18 and legally being able to make decisions and also worried about professionals excluding them from receiving information or making decisions for their family member (except when legal guardianship was awarded to the parents). In addition, families expressed their concern about the lack of accessible information about transition processes and their anxiety over the quality of adult medical services.

### Physician Concerns

The physician's concerns were around office schedules that do not allow enough time to see patients with complex issues and low Medicaid reimbursement. They also expressed concern over their lack of experience providing developmentally appropriate care and a lack of knowledge and experience treating patients with disabilities and SHCN.

### Recommendations

The stakeholder group developed recommendations to create more medical homes to increase the number of adult providers willing to accept medically complex patients transitioning from pediatric practices. They also suggested Health Maintenance Organizations (HMOs) need to make physicians more aware of the Operations Memorandum (Ops Memo) and Medicaid billing codes for transitional care visits during the patient transfer period. In addition, they suggested that transition tools for young adults, families and professionals be more widely accessible.

## Survey Responses

We used information from stakeholders to develop a survey to gather additional data from youth, families and medical providers.

ACHIEVA received survey responses from medical practices (over 160 physicians) that provide care for more than 232,000 patients across southwestern Pennsylvania. We also conducted one-on-one interviews with practices covering an additional 45,000 patients. More than 30 families also provided insight. Comments from these interviews and surveys are quoted throughout this report.

In addition to our surveys, in the 2013 Adult with Complex Transitions (ACT) Research Study done by the United Way of Allegheny County's 21 and Able Project almost all (95.8%) of the respondents to the ACT "individuals and family" survey said they were either "very interested" or "somewhat interested" in efforts to assist with medical transition. Nearly 100 respondents commented about the difficulty of medical transitions. Most of these comments referred to difficulties with insurance coverage, physicians' understanding of disability and physicians' assumptions that patients with complex needs are not capable of participation in their own health care decisions.

# SOLUTIONS AND RECOMMENDATIONS

**Medicaid must remain affordable and comprehensive for adults with disabilities.** Health insurance continues to be one of our nation’s highest priorities and it is especially important for people with lifelong disabilities and medical issues. Given the majority of people with disabilities and special health care needs are Medicaid beneficiaries, it is critical that affordable, comprehensive, continuous health insurance is available to them. Access should not be limited by work requirements or fees, as outlined in Healthy PA, which may restrict coverage for those with disabilities.

**“Insurance needs to be less complex and the information more easy to understand,” mom of M.**

The 2010 Patient Protection and Affordable Care Act (PPACA) health care reform legislation impacts coverage, access to care, and care coordination in the short-term and long-term. Specific provisions of the PPACA now in place expand access to coverage and ongoing care, including changes that permit children to remain on their parent’s insurance until age 26; eliminate an insurer’s ability to exclude coverage on the basis of pre-existing conditions; improve coverage portability; create a high-risk pool insurance for people who cannot access coverage through other sources; enhance Medicaid payment to primary care physicians; and mandate that nearly all people (including young adults) have coverage.<sup>7</sup> These provisions are critical and must remain available for people with disabilities and chronic medical conditions.

**“Medical Assistance needs to offer a higher reimbursement rate so we have more providers willing to care for our family members,” mom J.**

In addition, Medicaid reimbursement rates must increase and be more competitive with private insurance rates. Avik Roy, in his book, How Medicaid Fails the Poor (2013), notes that, in the average state, for every dollar that a private insurer pays a primary care physician to care for a patient, Medicaid pays 52 cents. This reduces the willingness of providers to accept patients with public insurance through the Medicaid program.

**The Pennsylvania Legislature should pass legislation to establish a part time Primary Health Care Practitioner Loan Repayment Program** through the Department of Health, using existing funds, as an incentive to recruit and retain practitioners to serve people with disabilities and other Medicaid recipients, especially in Pennsylvania’s underserved areas.

The current Primary Health Care Practitioners Loan Repayment Program (LRP), through the Department of Health, is a program which offers educational loan repayment to improve the recruitment and retention of primary healthcare practitioners in health professional shortage areas (HPSAs). These shortage areas are designated by the Health Resources and Services Administration as having shortages of primary medical care, dental or mental health providers and may be geographic (a county or service area), demographic (low income) or institutional (federally qualified health center or other public facility).

Eligible practitioners (general internal medicine, family practice, obstetrics/gynecology, pediatrics, dentists, certified nurse practitioners, physician assistants and certified nurse midwives) agree to be employed, at a site approved by the Department of Health, for a certain length of time for which they receive partial loan repayment benefits.

Currently the LRP requires full-time commitment of two to four years of service. Legislation that only requires a part-time commitment to receive a partial loan repayment benefit has been written by ACHIEVA and is currently being considered for introduction by a member of the Pennsylvania House of Representatives.

**The Pennsylvania Department of Education should ensure that an Individualized Health Plan is a component of the Individual Education Plan or 504 Service Agreement for students with disabilities or special health care needs.**

When youth transition to adulthood, it is typically assumed they are taking responsibility for their own health, including making doctor's appointments and managing their own treatment regimens. Moreover, as legal adults, they are typically entitled to make their own treatment decisions and enjoy privacy with respect to their medical appointments and records.<sup>7</sup>

**"I have had several experiences with many doctors talking to family/staff about my health issues before talking to me," self-advocate R.**

Young adults with developmental and intellectual disabilities must not be an exception to this rule. The American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians and American Society of Internal Medicine have stated that, "after the age of majority, all youth deserve to be treated as adults and to experience an adult model of care," even when they require decision-making support or are under legal guardianship.<sup>7</sup>

For the majority of school-aged children with disabilities and many with SHCN, an Individualized Health Plan should be a component of an Individual Education Plan or 504 Service Agreement. Therefore each year, beginning at age 14, the student's team including the student, family, school district personnel and support coordinators would be expected to discuss what actions should occur to plan for an effective health care transition. A video on these health plans can be seen at <http://pealcenter.org/resources/healthcare.html>.

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs, should ensure that Medicaid Managed Care Organizations and providers are aware of and in compliance with the requirements of the Operations Memorandum, effective since 2009.**

The Managed Care Operations Memorandum (OPs Memo) is an additional contractual requirement/clarification to the Pennsylvania Mandatory Managed Care (HealthChoices) Program. It provides guidance for transitioning medically-fragile young adults from pediatric to adult primary care providers and is monitored by the Pennsylvania Department of Public Welfare, Office of Medical Assistant Programs. It is meant to address the issues that youth and families with special health care needs may encounter during the transition between providers. A webinar at <http://www.personfirsthealth.org/initiatives> explains this in more detail.

For parents of youth with special health care needs, finding an appropriate adult doctor for their child can be a challenge. The OPs Memo affords youth the option of trying out an adult provider while their pediatrician is still providing care. The memo mandates that all Medicaid providers allow both physicians to bill Medicaid for reimbursement of services. This allows youth to remain connected to their pediatrician while they find the adult provider that can best accommodate their special needs. For physicians, treating youth with special health care needs, the memo allows for multiple reimbursable visits before the actual transfer of patient care occurs.

**"I had no warning that transition was coming for me. It was during a routine visit that the pediatrician's office informed me I would have to find a new physician because I would need to leave that practice," self-advocate S.**

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs, should establish and promote Medicaid billing codes** which allow physicians to bill for the extra time it takes to serve individuals with complex needs or individuals who need longer time to communicate on their own behalf.

Medical providers are concerned about compensation for the extra time needed to care for more complex patients. One solution to adequately compensate physicians for transition preparation and planning was highlighted in the Winter 2012 issue of *Keystone Physician* that provided proper billing codes for use by medical offices to cover regularly scheduled health maintenance visits (Current Procedural Terminology {CPT} codes 99394 and 99395). Here is that excerpt from page 51.

**“We need better communication and coordination between pediatric PCP and the adult PCP and this needs to be reimbursable time,” nurse D.**

For youth with special healthcare needs who have sufficient complexity to justify periodic Chronic Condition Management (CCM) visits, in addition to, health maintenance visits, health care transition preparation and planning are intended to occur during a CCM visit billed as a prolonged encounter with an established patient (CPT codes 99214 or 99215). Such visits can be documented as involving counseling for more than 50% of the visit. Youth with highly complex needs may require a CCM visit in which the counseling provided is devoted entirely to transition, but these visits are still reimbursable when using the prolonged encounter codes and the counseling rule.

Activity outside of the office encounters involved in the management of a youth’s transition plan (whether it stands alone or is incorporated into a more general care plan for a chronic condition) constitutes “care plan oversight.” Such work may involve phone calls to prospective adult primary care physicians or medical subspecialists, conversations with the youth and family regarding transition plans or communication with community agencies integral to the transition process. These activities can be billed by using care plan oversight CPT codes 99374 (15 to 29 minutes) and 99375 (> 30 minutes) through which the physician can bill monthly for the cumulative time spent on care (for transition) plan oversight. Similar coding and billing options may be exercised after the transfer of care from a pediatric medical home to an adult medical home.

As mentioned before, adequate Medicaid reimbursement rates must also be a priority.

**The Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs should urge all Medicaid Managed Care Plans to work with their physicians and physician groups to develop more adult and pediatric medical homes** for people with disabilities and special health care needs.

According to the National Center for Medical Home Implementation, a family-centered medical home is not a building, house, hospital or home health care service, but rather an approach to providing comprehensive primary care. In a family-centered medical home, the pediatric care team works in partnership with a child and a child’s family to assure that all of the medical and non-medical needs of the patient are met.

**“In the pediatric model we spend lots of time with patients and we do lots of hand-holding for families. Things just don’t work this way in the adult care world and that can be hard for patients with lots of medical needs,” Dr. S.**

Using the medical home as a tool, providers can enhance the organization of care and communication between pediatricians and adult medical providers. The medical home model offers the potential to address this issue by replicating the role of the pediatrician with the adult primary care physician as the hub. The increased use of the medical home model can improve access to health care, increase patient satisfaction and enhance health outcomes.

Care coordination, an essential component of the medical home model, requires additional resources such as health information technology and appropriately trained staff. Additionally, payment models that compensate for coordination activities encourage the use of this model.

Physicians should also be encouraged to use a portable, accessible, medical summary to facilitate the smooth collaboration and transfer of care among and between health care professionals. A webinar at <http://www.personfirsthealth.org/initiatives> explains this in more detail.

A joint statement from the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians and American College of Osteopathic Medicine identifies these core principles of the medical home:

- Each patient has a personal physician that knows them well and provides comprehensive care
- It is a physician-directed practice with a core team caring for the patient and their family
- Whole person orientation through caring for the patient across life stages
- Care is coordinated across multiple aspects of the health care system
- Quality and safety are incorporated in all aspects of the health care system
- Enhanced access to care through scheduling, convenience, hours and communication
- Payment reflects time and effort afforded by health care providers

**Medical schools in Pennsylvania need to continue to include education about health care transition for youth with disabilities and special health care needs** as part of the didactic and clinical training for medical professionals.

**“The biggest barrier is finding an adult PCP willing to take a patient with a disability or special health care needs,” nurse D.**

Adult medical physicians cited lack of education and training on specific disabilities, health care transition and caring for adults with developmental disabilities as a barrier. During clinical residencies, physicians need experience treating young adults with disabilities and chronic health issues in clinics and private physician practices. Once in private practice, physicians need ongoing training to enhance their knowledge of caring for adults with disabilities.

Given the enormous amount of information that medical students, residents and practicing physicians must acquire, on-line trainings have become efficient and effective tools for medical education. For example, the on-line training program created by the Florida Developmental Disabilities Council and the American Academy of Developmental Medicine and Dentistry is a free, 12 credit-hour webinar series for physicians that covers topics such as best practices in the care of adults with developmental disabilities, strategies for addressing the psychological and support needs of adults with special health care needs, practical strategies for providing care in medical offices, clinics and other medical facilities, and effective billing and reimbursement practices. The series is designed to enhance the practice skills of primary care physicians and residents who would like to provide better care to their adult patients with developmental disabilities.

Each of these FREE webinars is accredited by the American Academy of Family Physicians for professional development hours with a total of up to 12.0 credit hours available to those who participate in all of the webinars at: <http://aadmd.org/page/pedd-webinar-series>.

# ADDITIONAL RESOURCES FOR YOUTH WITH DISABILITIES, FAMILIES, PROFESSIONALS AND INSURERS

In addition to the solutions outlined in this report, the following resources are available to assist everyone involved in this healthcare transition process.

## What can families do?

Pediatric medicine is seen as being very family-oriented. Even though adolescent patients spent increasing amounts of time alone with pediatric providers, families generally saw themselves as having an ongoing and involved role in the

provision and delivery of care. When a young person turns 18 and has the legal right to sign documents and make medical decisions without parental input, it creates additional stress for families. Alternately, adult-oriented providers' focus on the individual patient often left parents and families without a formal role in treatment and limited their ability to share important knowledge with adult-oriented providers.

**“It can take 2 to 3 years before they are comfortable with moving on from a pediatric practice and we need to begin to get them ready before age 18 and this is often when families are overwhelmed with education and employment issues also,” nurse D.**

## Consult an attorney.

Families may want to consider speaking with an attorney who has experience with special needs trusts, power of attorney and limited medical guardianships as their child approaches age 18.

## Contact their Special Needs Unit.

Families can always contact their health insurance plan's Special Needs Unit (SNU). In Pennsylvania, Medicaid is also known as Medical Assistance. If you have Medical Assistance in Pennsylvania you have access, through your health insurance plan, to a Special Needs Unit. The SNU, mandated by the

Pennsylvania Department of Public Welfare, is a separate unit of the managed care plan that assists members with access to health care, coordination of health care and locating providers and community resources. It is typically staffed by social workers and case managers that often have medical backgrounds. They are mandated to respond to members needs within 48 hours of initial contact and they serve as advocates for medical services. A webinar at <http://www.personfirsthealth.org/initiatives> explains this in more detail.

**“Pediatrician knew our son for his whole life. PCP doesn't have much information and is not aware of the family's situation in caring for our son so new PCP can not offer much information to help us,” mom Christina.**

## Use the Tools.

Families should also be aware of several on-line resources to guide them through the transition process. There are a series of on-line videos that highlight health care transition which was created by the Parent Education and Advocacy Leadership (PEAL) Center. This library contains five videos covering self-determination; moving from pediatric to adult providers; Individualized Health Plans; health insurance and service eligibility; and Medical Assistance and the OPs Memo. Videos available at <http://pealcenter.org/resources/healthcare.html>.

Another on-line resource is the Pennsylvania Secondary Transition website at [www.secondarytransition.org](http://www.secondarytransition.org) which includes a document that families can use to enter text and build a transition plan. Managed by the Pennsylvania Training and Technical Assistance Network (PaTTAN), this tool was developed in 2012. This site is a continual work in progress and includes more than 21 core documents in both English and Spanish to help families navigate the transition process. It includes links to many agencies and resources and also lists information on various local transition coordinating councils.

**“There are resources out there but no coordinated effort to make us aware of what these resources are and how we can get support. We don’t even learn about agencies that could help us,” says self-advocate S. “It just seems logical that a medical office needs to provide some of that care coordination.”**

Another tool for youth and families is the Transition to Adult Living in Pennsylvania booklet (revised in 2012). The publication is available at [www.secondarytransition.org/topic/health](http://www.secondarytransition.org/topic/health). This booklet, created by the Pennsylvania Departments of Health, Education, Public Welfare and Labor & Industry, can be copied and distributed for use as a transition tool. It includes a working checklist that families can use to create a transition roadmap covering self-advocacy, health and wellness, community living, money management, employment, medical management and activities of daily living.

**“Health care transition is more than just picking a new doctor. You need to get a Pennsylvania identification card made. You need to go to court and get guardianship if the child is permanently incapacitated, you need to make sure the county, doctors and insurance company all have copies of that guardianship or Power of Attorney so you can communicate on your child’s behalf, ” mom of L.**

## What can youth do?

Youth with disabilities and chronic health conditions reported concerns centered on establishing relationships with adult-oriented providers and bringing a new team of providers up to speed. They also reported concerns about transitioning to a system in which they would have to manage multiple providers rather than receive services from a single provider or a comprehensive (and often specialized) clinic.<sup>8</sup> Additionally, young people often reported parental difficulty and stress with the transition from pediatric to adult-oriented health care. This parental difficulty with transition, in turn, created stress and discord for young people.<sup>6</sup> This stress, combined with the stress that young people with disabilities and chronic health conditions already experience managing their care in a more difficult to manage adult health care system, creates a situation in which the transition to adult-oriented care is very burdensome.

**“I am not asking the doctor to know specific information about my disability, but to look at me as someone that needs routine care too,” says self-advocate V.**

### Develop self advocacy skills.

There are organizations to help with leadership development such as the Pennsylvania Youth Leadership Network (PYLN) and Children’s Hospital Advisory Network for Guidance and Empowerment (CHANGE). The PYLN is a team of youth leaders with disabilities from across Pennsylvania who work to develop the self-determination, empowerment and leadership of youth to promote successful post school outcomes in areas of education, employment, independent living and health and wellness among youth and young adults. CHANGE is a youth-led and driven initiative that advises young people, families and professionals about the transition process. It works to ensure successful transitions to adult lives for individuals who may face transitional barriers in health care.

**“Physicians need more sensitivity training in how to care for those with special health needs. Even simple accessible equipment could go a long way,” says self-advocate E. “A Hoyer lift is a simple thing and needed for patient transfer even to get me on the exam table.”**

**“I often feel I get subpar care because they just don’t know what to do with me. They skip getting my weight to avoid transfer issues. The trach and ventilator seem to trigger slight panic even when I am not there for those issues and I have a personal care aide with me,” self-advocate J.**

## What can physicians do?

### Support families.

If medical providers would begin and continue to promote widely available transition tools, families could be more adequately supported during the transition process. Physicians need to support families through the transition process and provide guidance.

### Communicate.

Participants also reported there was very little communication between pediatric providers and adult-oriented providers, which affected the transfer of knowledge between pediatric medicine and adult-oriented medicine and made referral to adult-oriented providers more difficult. Communication patterns between providers were influenced by residency training, continuing education, professional meetings and the physical separation between pediatric and adult-oriented treatment spaces.

**“Better communication between specialists and primary care doctors, so everyone understands my treatment plan, would be nice,” self-advocate E.**

### Get training.

Young people and their families who sought adult-oriented providers reported that it was very difficult to find adult-oriented providers who matched their pediatric providers in their knowledge about, training in and experience with their disability or special health care need.<sup>8</sup> This may be because adult-oriented providers lack experience with or knowledge of childhood-onset disabilities and/or chronic health conditions, which can be attributed to different training and residency experiences of pediatric and internal medicine residents.

**“Our biggest drawback is finding doctors that are really comfortable taking on a patient with special and complex needs,” Dr. A. “Many physicians just don’t have experience dealing with patients with special health care needs.”**

### Adopt the medical home model.

There are more than 140 pediatric practices in 48 counties in Pennsylvania that have been trained in the Maternal and Child Health Bureau medical home principles through the Pennsylvania Chapter of the American Academy of Pediatrics Medical Home Program, which is funded by the Pennsylvania Department of Health and the Health Resources and Services Administration (HRSA) [www.pamedicalhome.org](http://www.pamedicalhome.org).

There continues to be a need for more medical homes, especially adult providers. Many practices may be operating at this level, but have not called themselves medical homes, even though they are providing care coordination services.

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**“Guardianship can be a barrier when it comes to adult medicine and we have had patients that get upset when they are dealing with adult providers and realize that adult providers are not required to share information with anyone other than the patient when the patient reaches the age of 18. Adult doctors need to understand the functioning level of the patient and that working with the family is often the best practice when competency is in question. Legal guardianship is an expensive process that many families cannot go through,” Dr. S.**

## What can Insurers do?

**Implement the Ops Memo.** Medicaid providers need to be compensated for the additional time and/or staff they may need to adequately meet the needs of their patients with disabilities and chronic, complex medical issues. One solution is better use of the existing OPs memo for transition billing, which provides for reimbursement during the transfer process between providers. The OPs memo defines “medically fragile” as any youth who has or is at risk for a chronic physical, developmental, or behavioral condition and requires more medical support than a generally-healthy child. Under the OPs Memo, in 2009, the Medicaid Managed Care Organization is:

- Responsible for identifying all medically fragile members who are receiving primary care services from a pediatric provider by at least the member’s 18th birthday.
- Responsible for outreach to medically fragile members and or the member’s guardian to assist in identifying a qualified adult provider to transition care from a pediatrician to an adult provider.
- Responsible for maintaining members who cannot be transitioned by their 21st birthday in active case management until the transition is accomplished.
- Required to develop payment mechanisms to enable both pediatric and adult care providers to receive payment for medically necessary services provided concurrently during the transition process.

**Eliminate coverage lapses.** According to the 2009-2010 National Survey on Children with Special Health Care Needs, the vast majority of youth with special health care needs are insured. Coverage, however, is usually subject to age-related cutoffs and may therefore expire in young adulthood.

Youth who have health care coverage through their parents’ private health insurance plans must obtain independent coverage after age 26 (PPACA). Youth enrolled in the Children’s Health Insurance Program (CHIP) become ineligible for coverage at age 18; although, some states extend Medicaid coverage until the age of 21 for full-time students. Access to public health insurance through funding from states’ Title V Children with Special Health Care Needs Programs typically ends at 21 regardless of a young person’s employment or education status.<sup>3</sup>

Access to public health insurance through Medicaid is dependent on eligibility for Supplemental Security Income (SSI) benefits. After age 21, eligibility criteria for SSI (and thus Medicaid) becomes more stringent and the amount, duration and scope of services funded by Medicaid for individuals over age 21 become less comprehensive and more restrictive.

These age-based eligibility requirements have historically contributed to widespread loss of insurance when youth reach adulthood, regardless of disability. The Commonwealth Fund Survey of Young Adults in 2009 found that 30% of previously insured young adults became uninsured upon graduating from high school. This is in addition to the 15% who were required to transition to a new source of coverage, nearly half of whom experienced a gap in coverage. The majority of those gaps lasted one year or more.<sup>9</sup> A separate study in 2007 found that nearly 30% of all individuals between the ages of 18 and 24 years of age were uninsured, compared to only 12% of children under the age of 18.<sup>3</sup>

**“Dynamics of insurance are different for different carriers and durable medical equipment can present unique challenges. We need insurance companies to work together to make it easier on the family,” nurse R.**

Ensuring continuous coverage may require careful advance planning especially for youth who rely on Medicaid based solely on family income. These youth typically “age out” of their previous source of health insurance after the age of 18 or 21, many years before their privately insured counterparts who may remain covered under their parents’ health plans through age of 26. Moreover, young adults with disabilities are at high risk of unemployment or underemployment and as a result may experience significant difficulty obtaining employer-based health insurance.<sup>10</sup>

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## Bibliography

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*This project is supported by a grant from the FISA Foundation.*

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