



Primary Care Providers' Perspectives on Serving Young Adults with Special Health Care Needs

Washington State Department of Health, Division of Community and Family Health, Office of Maternal and Child Health, Children with Special Health Care Needs Program, July 2009

Background and Methods

In Washington State, an estimated 14 to 17 percent of children age 17 and younger have a special health care need.^{1,2} As youth with special health care needs grow into adulthood, they need to successfully move from pediatric care into adult health care. Health care providers, families, and young adults have identified many barriers in this transition. Some barriers reported by youth and their families include lack of adequate health insurance coverage, lack of care coordination, and inability to access needed care.³ Barriers reported by health care providers include reimbursement issues, lack of knowledge about transition planning, and not being comfortable providing care for patients with chronic childhood illnesses. Providers also report lack of training or resources to effectively treat young adults with special health care needs and poor communication across providers and systems of care.^{4,5,6} In addition, families, youth, and pediatricians may be reluctant to end their long-term patient-provider relationship.^{7,8} Only 47 percent of youth with special health care needs age 12-17 in Washington State receive the services necessary to make a successful transition to adult care, work, and independence.⁹

The American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and the Society for Adolescent Medicine recognize the importance of transition of youth with special needs to adult care.

In 2008, the Washington State Department of Health surveyed primary care providers who see adult patients in Washington. The purpose of this survey was to learn about ways to increase and improve adult health care services for young adults with special health care needs, like childhood onset chronic illness or developmental disabilities. Sampled providers included physicians, nurse practitioners, and physician assistants in rural and urban¹⁰ areas of the state. We also surveyed physicians that have the combined specialty of pediatrics and internal medicine (Med-Peds). Providers received three mailings: a pre-survey letter (day 1), the survey and cover letter (day 8), and a reminder post card (day 18). We sent 641 surveys and received 98 responses (15 percent response rate).

Provider type	Response rate	n
Urban physicians	11%	11
Urban internal medicine physicians	7%	18
Urban nurse practitioner or physician assistant	16%	17
Rural physicians	17%	20
Rural internal medicine physicians	10%	7
Rural nurse practitioner or physician assistant	18%	10
Med-Peds Physicians	26%	5
Unknown	-	10
Overall	15%	98

A health provider database supplied names and addresses for survey distribution. Quantitative data were analyzed with Microsoft Excel and qualitative data were analyzed using NVIVO 8.

Results

Barriers in caring for patients with childhood onset chronic illness or developmental disability

Financial and Documentation Barriers

- Lack of adequate compensation for caring for young adults with special needs, particularly those with Medicaid. Some respondents dealt with this barrier by limiting the number of patients with Medicaid from their practice or not accepting patients with Medicaid at all.

“With the persistent rise in overhead and stagnant or reduced reimbursement, we can't continue to take on under/ non-insured patients and keep our doors open.” - Internal medicine physician

“If it was reasonably reimbursed the organization I work in would not limit us on accepting a higher percentage of Medicaid insured patients.” - Family practice physician

“There is nothing I can do, we need a certain income in order to keep the clinic open; this is not negotiable. These patients require a lot of time.” - Family practice physician

- Non-reimbursement for required paperwork and documentation, specifically for patients with Medicaid.

“Low reimbursement, consuming paperwork and difficult cases all contribute to not accepting those patients into our practice.” - Family practice physician

“The additional paper work, phone calls, coordination of services is an un-reimbursed paperwork nightmare - and I already drown in paperwork.” - Internal medicine physician

- Internal medicine physicians reported the largest barriers to accepting young adults into their practice were lack of insurance, Medicaid paperwork, or Medicaid reimbursements. Physician Assistants and Nurse Practitioners reported the least barriers.

Other barriers

- Lack of provider experience, support, time, or lack of collaboration with specialists for caring for these patients with higher needs.

“These patients are all time intensive and require collaboration with multiple other specialists, therapists and durable medical.” - Internal medicine physician

- Lack of transportation for patients to get to and from appointments.

“Mobility is our biggest issue. If clients can get to our clinic we can provide primary care.” - Nurse Practitioner

- Lack of caregiver knowledge and involvement.

Providers' needs

- Assistance from other professionals such as specialists, social services providers, and mental health providers. The need for mental health providers was mentioned frequently by providers in the Eastern part of Washington.

"The main issue with this is the lack of available psychiatric practitioners, especially for children or teens." - Nurse Practitioner

"Specialist support such as for patients with neurological or psychiatric complex medications." - Family practice physician

"A specialty clinic from a pediatrician who knows the patient sending a detailed summary of current medical problems and current plan of management." - Family practice physician

- Care coordinators in their office.
- Community resources.
- Adequate reimbursement.

What's currently working

- Education, training, or experience.

"Spend time each year performing continuing education hours enhancing knowledge." - Family practice physician

"Have been in the medical field for more than 25 years; personal experience." - Physician's Assistant

- Successful collaboration with specialists.

"Consultants from Children's Hospital and local neurologists have been helpful with behavioral problems." - Med-Peds physician

"We have team approach working with Social Workers, MDs, Dietitians and RN - each member of the team offers tools and experience to care for these complicated patients." - ARNP

"Consultation with psychiatry for behavior management issues." - Family practice physician

- Involved families and caregivers.

"Family support makes the most difference in providing care to those patients." - Nurse Practitioner

“(The) family support of patient is most helpful.”- Family practice physician

“Caregiver comes to office visits with paperwork, staff reports, etc” - Internal medicine physician

- Making practice changes, like providing longer appointment times and other accommodations to patients.

*“(We) use computer in exam room to type notes to patients in very large type and show pictures.”
- Internal medicine physician*

“We schedule longer visits.”- Family practice physician

“Patients in this practice who do not qualify for some type of insurance or state assistance usually qualify for discount services.”- Physician's Assistant

- Ability to access professional resources through the Internet or fact sheets.

Conclusions

This report documents the challenges of transitioning adolescents with special health care needs into adult care in Washington State. Many of the barriers health care providers experience, such as difficulties with reimbursement, lack of experience and knowledge, and lack of specialist support have been documented in the literature and by other states.^{3-8,10,11} These represent significant challenges for youth and their families. Although financial issues were the most frequently mentioned barrier by health care providers, vastly improved reimbursement rates alone would not eliminate all the barriers to successful transition.

Based on the information from this survey, transition of young adults from pediatric to adult care may be improved by increasing parent-provider relationships in the medical home, provider reimbursement, and provider training – all areas the Department of Health and partners are working to improve. Survey respondents noted the key role parents and families play in improving transition and care; a similar study in Massachusetts describes the role of parents and guardians as “educators of health care professionals.”³ We also know that strong parent-provider relationship increases the likelihood of having adolescent transition issues addressed.¹²

This survey confirms that a multi-pronged approach is needed to prepare youth and their families for the challenges ahead and prepare adult providers to accept youth and young adults with special needs into their practices.

Potential Solutions

Reimbursement

The most frequently mentioned barrier to providing care was the low reimbursement rate and non-reimbursed time needed to care for patients with Medicaid.

The Department of Health and partners are addressing this by getting information from providers about their needs, assisting in implementation of legislation that assures coverage for more children and young adults and more billable components of services, and providing information to young adults and families about insurance options.

Provider Training

Providers report training is helpful in caring for patients with special needs. The Department of Health partners with the Adolescent Health Transition Project and the Medical Home Project at the University of Washington Center on Human Development and Disability to provide web-based information for providers and families. These resources can be accessed at <http://depts.wa.edu/healthtr> and www.medicalhome.org. A guide for transitioning adolescents and their families is the *Adolescent Health Transition Notebook*, also available at <http://depts.wa.edu/healthtr/notebook>. The Center for Children with Special Needs at Seattle Children's Hospital and Regional Medical Center (www.cshcn.org) offers care plans and other resources for teens.

Medical Home

Information from this survey reinforces the importance that every child has a medical home.¹³ Providers reported that family involvement in the child's care and collaboration and communication between primary care provider and specialist help the provider care for patients with special needs.

Awareness of the need for medical homes for children continues to grow in Washington. Successful legislation passed in 2008 to enroll primary care providers in medical home learning collaboratives. The learning collaborative is a short-term (6–15 months) learning system that brings together teams from hospitals or clinics to focus on a specific topic. In this case, how to become a medical home. Assuring adolescents have a medical home should improve their transition to adult health care.

Limitations

Because of the low survey response rate (15 percent), information from this survey cannot be generalized to all health care providers in Washington. In addition, responders may be biased toward those with more experience or with strong opinions about this topic, compared with non-responders. However, since the main purpose of this survey was to learn about solutions to the difficulties of adolescent transition to adult care, those that have experience or interest in this topic would likely provide the most useful information.

¹ Children and youth with special health care needs are those who have chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children and youth generally.

² Data from the Washington State Department of Health. *The Health of Washington State, Children and Youth with Special Health Care Needs*. (2007)

³ *Left Out in the Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts*. (2008). The ARC of Massachusetts.

⁴ Okumura, M. J., Heisler, M., Davis, M. M., Cabana, M. D., Demonner, S., & Kerr, E. A. (2008). Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*, 23(10), 1621-1627.

⁵ "Adolescent Transition and Transfer to Adult Healthcare" Office of Special Healthcare Needs, Rhode Island Department of Health. (2007)

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- ⁶ Reiss, J., & Gibson, R. (2002). Health care transition: destinations unknown. *Pediatrics*, 110(6 Pt 2), 1307-1314.
- ⁷ McManus M, Fox H, O'Conner K. (2008) *Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Care*. The National Alliance to Advance Adolescent Health. Fact Sheet No. 6.
- ⁸ Burke, R., Spoerri, M., Price, A., Cardosi, A. M., & Flanagan, P. (2008). Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clin Pediatr (Phila)*, 47(4), 347-354.
- ⁹ Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved 12/22/2008 from www.cshcndata.org
- ¹⁰ Urban and rural classification was determined using provider zip codes matched to Rural Urban Commuting Area Codes (RUCA). For more information, see <http://www.doh.wa.gov/data/Guidelines/RuralUrban.htm#Ruca>.
- ¹¹ Peter, N. G., Forke, C. M., Ginsburg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: internists' perspectives. *Pediatrics*, 123(2), 417-423.
- ¹² Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115(6), 1607-1612.
- ¹³ Medical Home is an approach to delivering primary health care through a team partnership that ensures health care services are provided in a high quality and comprehensive manner.

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