



White Paper on the Transition from Pediatric to Adult Health Care

MINNESOTA DEPARTMENT OF HEALTH

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White Paper on the Transition from Pediatric to Adult Health Care

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Executive Summary

In Minnesota, an estimated 112,537 youth (approximately 25.6 percent of 12-17 year-olds who live in Minnesota) currently navigate through adolescence with a special health need, and will need to transition from a pediatric to adult-centered model of health care.¹

Health care transition is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician. A successful transition, composed of three main phases (transition planning and preparation, transfer of care, and integration into adult health care/transition completion), lays the groundwork for positive health outcomes in adulthood.

This paper provides data on the status of health care transition in Minnesota and then presents recommendations to improve the system.

Findings

According to the 2016-2017 National Survey of Children's Health, only 23.3 percent of youth with special health needs in Minnesota receive the recommended supports needed to prepare for and transition to adult health care.¹

Potential factors in Minnesota and across the nation that contribute to the lack of transition planning and readiness are presented in this paper and include:

- Minimal standardization of transition practices across primary and specialty care clinics,
- Limited knowledge about health care transition among youth, parents, and health care providers,
- A lack of adult health care providers who will accept youth with complex health needs, and
- Barriers in payment methodologies and infrastructure that prevent innovative strategies to improve transition.

Recommendations

Recommendations to improve the experience and outcomes of health care transition include:

- Improve data systems for better evaluation and measurement of health care transition,
- Establish a Minnesota cross-sector health care transition coalition,
- Build skills and knowledge in youth to advocate for themselves and their families,
- Increase education and training opportunities for health care providers, and
- Address gaps in the current infrastructure.

¹ Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved from www.childhealthdata.org. CAHMI: www.cahmi.org.

Introduction

Adolescence is a period of rapid change, development, excitement, and sometimes fear and confusion. For youth with disabilities, chronic conditions, or other special health needs, this period is especially complex, as youth and families navigate the transition from childhood to adulthood alongside chronic condition or disease management (Oswald, Gilles, Cannady, Wenzel, Willis, Bodurtha, 2013). Health care transition is complex for those with chronic conditions; however, a successful transition lays the groundwork for successful, lifelong positive health outcomes.

This paper addresses the importance of an organized, coordinated health care transition through the presentation of research and data on the needs of youth with special health needs and their families during this critical adolescent stage. It presents the relationship between transition and positive adult health outcomes, and the manner in which a lack of transition planning contributes to health disparities throughout adulthood. The paper concludes with transition-focused recommendations to optimize short and long-term health outcomes for youth with special health needs.

Youth with Special Health Needs

Of the approximately 6.1 million youth with special health needs in the United States (24 percent of all youth in the United States), it is estimated that approximately 500,000-750,000 become adults annually (Acharya, Meza, & Msall, 2017; Bloom, Kuhlthau, Van Cleave, Knapp, Newacheck, and Perrin, 2012; Child and Adolescent Health Measurement Initiative, 2018). Youth with special health needs are those youth who have, or at increased risk for, a chronic physical, developmental, behavioral, or emotional condition. They also require health or related services beyond that generally required. In Minnesota, an estimated 112,537 youth (approximately 25.6 percent of 12-17 year-olds who live in Minnesota) currently navigate through adolescence with a disability, chronic condition, or other special health need (Child and Adolescent Health Measurement Initiative (CAHMI), 2018). For these Minnesota youth, a smooth transition from pediatric to adult-centered health care is essential for healthy adult outcomes. Youth with special health needs include both those who have the capacity to manage their own care and those who, due to their physical, developmental, emotional, or behavioral health condition, do not have the capacity to manage their own care.

Health Care Transition

“Health care transition” is the process through which youth move from pediatric to adult-centered health care. Health care transition forms the framework for healthy adult outcomes through appropriate, sufficient and successful access to necessary preventive and condition-specific adult care.

Three phases comprise health care transition: (1) transition planning and preparation, (2) transfer of care, and (3) integration into adult health care. Each of these phases has unique barriers to success and opportunities for improvement. Health care transition is similarly important as compared to other adolescent transitions, like the transition from education to employment. However, unlike other transitions, deliberate planning and preparation, transfer, and actual completion of health care transition frequently lacks. It is important to recognize that transition is a complex, multi-faceted process that involves all aspects of life:

training/education, employment, community living, relationships and networks necessary for an inclusive, productive life.

Methodology/Sources

This paper presents data collected from a mixed methods approach. A literature review, analysis of the National Survey of Children’s Health, and statewide key informant interview qualitative responses, conducted specifically for purposes of this paper, are presented. Cumulatively, this data provides a comprehensive description of health care transition and recommendations for improvement of the health care transition process in Minnesota. Of note, with the exception of the seven (3 providers, 4 parents) key informant interviews, the majority of research and data in this report are national in scope. While the report includes some Minnesota-specific data, availability is limited or comes from sources with sample sizes too small to generalize or report.

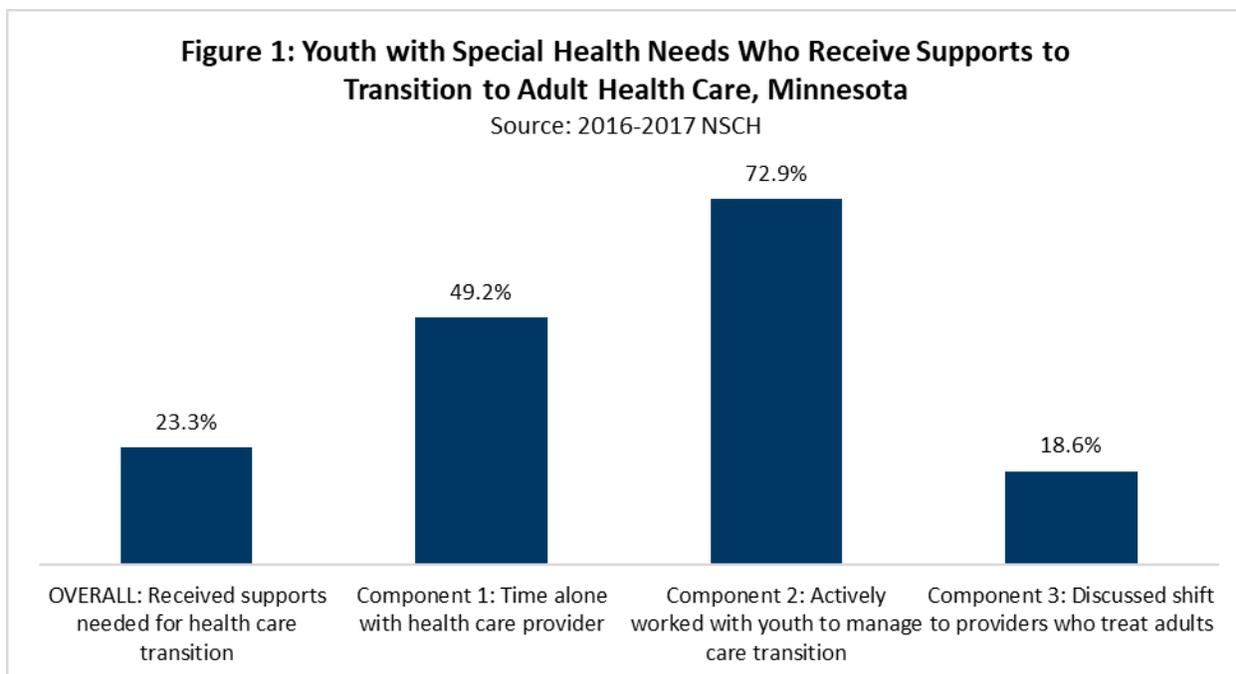
Findings

Only one in five Minnesota youth receive the recommended supports needed to prepare for and transition to adult health care

According to the most recent National Survey of Children’s Health (NSCH) data, only 23.3 percent of youth with special health needs in Minnesota received the recommended supports needed to prepare for and transition to adult health care (compared to 16.7 percent nationwide).² The three main areas used as a proxy measure for health care transition in the NSCH are: 1) the youth had time alone to speak with the health care provider (doctor) during his/her last preventive visit, 2) the health care provider actively worked with the youth to gain skills to manage his/her health care or understand the changes in health care that occur around age 18, and 3) the health care provider discussed the shift to health care providers who treat adults, if needed (CAHMI, 2018).

Figure 1 shows the percentage of youth with special health needs in Minnesota reported by their parent/caregiver as meeting the overall health care transition outcome, as well as the three components. Around 73 percent of youth with special health needs were reported as having had their doctor actively work with them to gain skills and understand changes in health care. This is compared to 49.2 percent were reported as having had time alone with doctors, and only 18.6 percent were reported as having discussed the shift to clinicians who treat adults (CAHMI, 2018).

² The NSCH “provides rich data on multiple, intersecting aspects of children’s lives—including physical and mental health, access to quality health care, and the child’s family, neighborhood, school, and social context.” Responses are given by parents/caregivers in the household who are knowledgeable about the health and well-being of the youth.



Disparities exist in the implementation of best practices in health care transition

While health care providers are increasingly aware of health care transition's importance in the immediate and long-term health outcomes of youth with special health needs, clinicians still report gaps in knowledge in issues around adolescence and transition. For instance, in a recent report of the American Academies of Pediatrics and Family Physicians and the American College of Physicians, authors summarized current literature studying barriers to transition as experienced by families and physicians. One of the major barriers reported by clinicians was around training limitations. This included a lack of knowledge and/or training on best practices in health care transition, pediatric-onset conditions, adolescent development and behavior, psychosocial needs of young adult adults with conditions, and working with adult patients who are reliant on caregivers (White & Cooley, 2018).

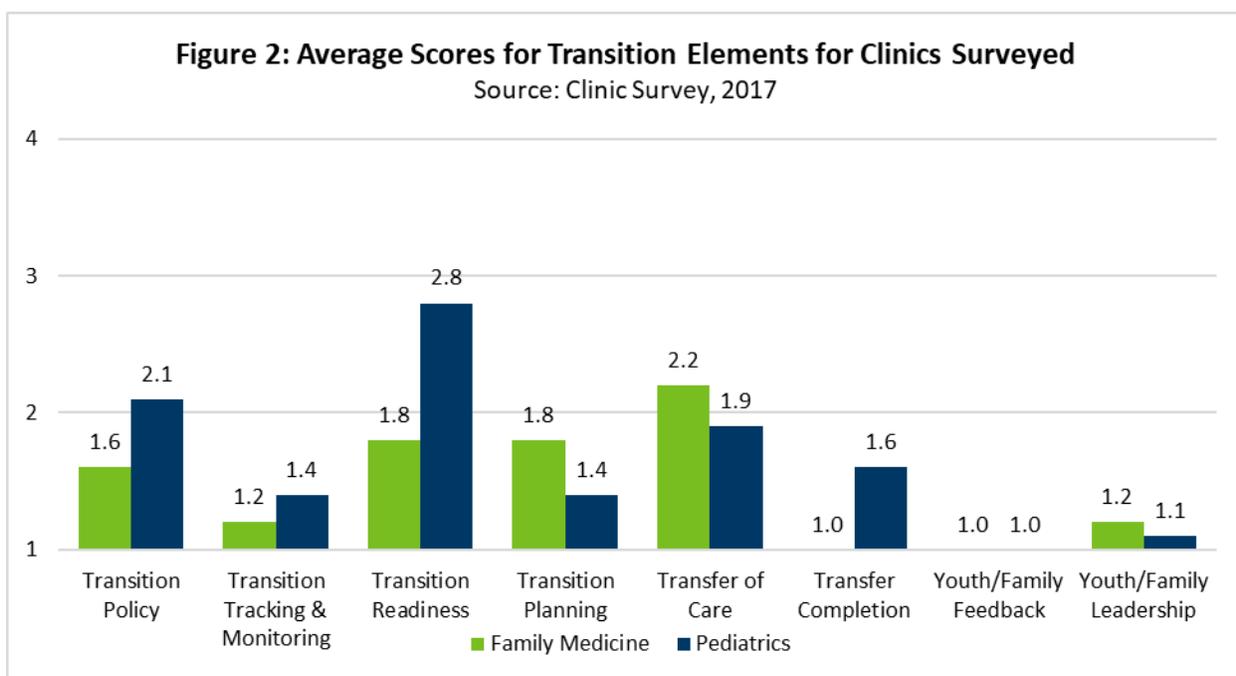
During key informant interviews, Minnesotan parents frequently referred to the clinicians' seeming lack of transition knowledge or experience. One parent explained:

I have found that conversations with our medical providers have been awkward and I am not sure the providers have much knowledge to share about the topic.

This lack of training contributes to a lack of standardization in practice of care around health care transition. In Minnesota, assessments conducted with primary care clinic staff and families of youth with special health needs highlight the lack of health care transition standard practices for youth with special health needs.

A 2016 assessment conducted with five Family Medicine and six Pediatric clinics demonstrated the need for improvement in all areas of transition. For this assessment, participants completed

the *Current Assessment of Health Care Transition Activities* survey instruments.³ These instruments include questions on the *Six Core Elements of Health Care Transition*, which include transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer and integration into adult-centered care, and transition completion and ongoing care with an adult clinician, plus two additional items that address youth and family feedback and leadership within a clinic. Clinics self-rated on a scale from one (basic – no policies or protocols) to four (comprehensive – standardized implementation). Though conducted with a small clinic sample, overall findings (in Figure 2) suggest that both Family Medicine and Pediatric clinics self-reported low overall scores in the implementation of the *Six Core Elements of Health Care Transition*, particularly in transition transfer completion and youth/family feedback.



Qualitative key-informant interview data from 2018 – 2019 reflects similarly. A physician who participated in an interview reflected on experiences within his clinic and stated:

Among providers, there is a lot of improvement opportunity for completion of the transition through a warm handoff within the same system, and Med-Peds⁴ doctors can play a huge role in the transition process for children and youth with complex care needs. At the same time, though, even anticipation of the transition point is difficult. Different health practices within the Twin Cities⁵ each have their own line as to when they will not see patients any longer. Some are 18, some are 26. This creates a fractured line, which, at the state level, seems fixable. The actual transition age needs to be known to be anticipated.

³ The *Current Assessment of Health Care Transition Activities* tool is available at www.GotTransition.org

⁴ Med/Peds doctors, also known as internal medicine-pediatrics, are a medical specialty in which doctors are board certified in both pediatric and internal medicine.

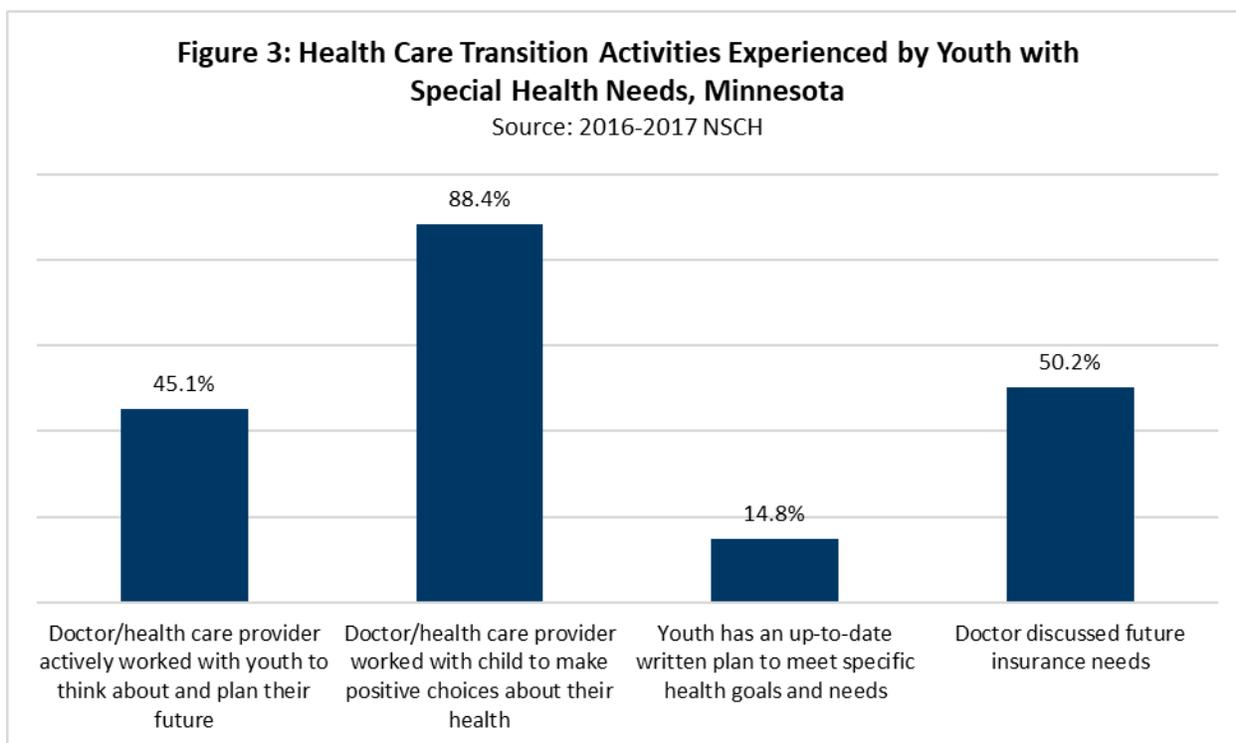
⁵ Minneapolis-Saint Paul metropolitan area

A parent of a transition-aged youth shared her frustrations during an interview, and reflected:

I cannot fathom what barriers or challenges (health clinics) face that make it impossible for them to provide my son with the information, resources, and guidance he needs to successfully transition to adult health care... The “care” that my son receives is sick care, judging by the times my son sees his pediatrician. The complete silence from my son’s pediatrician during this critical time of his transition to adult health care is only further evidence of the way he has been “treated” all along.

Like the survey data, these key informant interviews demonstrate that health care transition planning is not, but should and can be, a standard practice among clinicians in Minnesota.

The NSCH also measures other best practices related to health care transition. The 2016-2017 NSCH found that families of youth with special health needs did not report receipt of other best practices associated with effective health care transition (see Figure 3). As Figure 3 reflects, only around 45 percent of families of youth with special health needs reported their doctor or health provider worked with their youth to think about and plan for the future, although 88 percent reported that their doctor worked with their youth to make positive choices about health. Around 50 percent of families of youth with special health needs reported discussions with their provider around future insurance needs. Shockingly, less than 15 percent of families of youth with special health needs reported an up-to-date written plan to meet specific health goals and needs (CAHMI, 2018).



Furthermore, a key informant interviewee reflected:

Individual providers and family members often lack awareness and training about how to combine person-centered planning AND realistic observation and assessment of

functional skills – they may rely too much, or not enough, on the young adult’s self-assessment and wishes; they also may rely too much, or not enough, on the findings of informed observers including parents, teachers, therapists, evaluators, physicians, social service providers, etc. – it’s a trick to obtain and integrate ALL of the relevant available information in order to create a coherent, effective, transition plan.

Disparities in health care transition persist for youth with special health needs will persist without intentional, dedicated efforts that research, establish, and follow health care transition best practice guidelines. This includes partnership with families of and youth with special health needs to plan for the future and develop an up-to-date written plan.

Youth and families report they do not feel prepared for health care transition

White and Cooley (2018) describe fear amongst families of a new health care system and/or hospital as a barrier to successful transition. This manifested in families as they reported not wanting to leave their pediatric clinician and institution; having anxiety about how to relinquish control around managing their youth’s condition; and having anxiety around not knowing adult clinicians and the adult health care system (White & Cooley, 2018). Some of these fears and anxieties could be eased by providing education and guidance to youth and families so they can feel more prepared for transition.

An important aspect of health care transition is providing education and guidance to youth and families not just related to the transition process, but also related to general physical and mental health care and needs, diagnoses, adult health systems, and other relevant topics. Studies have shown that transitioning youth and their parents do not receive health care transition counseling, nor did they know enough in advance of the transition point about transition. They also reported having a lack of knowledge about their medical diagnoses. A study on transition for youth with congenital heart disease found that only 39 percent of youth and 51 percent of their parents had adequate knowledge of the disease (Yang, Chen, Wang, Gau, & Moons, 2013). These experiences were reiterated by clinicians and families throughout key informant interviews. One provider reflected on this lack of preparation, and expanded further on the difference between family-centered care in pediatrics versus patient-centered care in adult medicine:

From the perspective of someone who’s worked in pediatric hospitals all my life, the lack of effective “hand off” operations for most patients who are graduating from pediatric to adult health care is a HUGE problem – there’s no funding to cover staff time to help the patients and families plan this, find a new doctor, visit that doctor, help explain the personal and family dynamics to the doctor. Also, pediatric systems of care tend to be family-centered and include parents or other caregivers constantly and automatically, whereas adult systems of care tend to focus on the individual patient and are set up to preserve that individuals autonomy, privacy, and confidentiality – which typically means deliberate exclusion of other family members. This can even be a problem for an adult under guardianship but it’s a huge problem for adults who might not meet criteria for guardianship but still need quite a lot of parental or family support

for complex, emotionally intense decisions (and to avoid exploitation or even abuse by unscrupulous providers or systems).

Families reflected similarly, and one parent commented on the toll that a lack of transition planning and information takes on her family. This parent shared:

I cannot speak to what barriers or challenges the State of Minnesota faces that make it impossible . . . to provide my son with the information, resources, and guidance he needs to successfully transition to adult health care. I can only state that this failure is coming at a cost to my son and to my family. He is lost, and we are lost.

Healthy adult outcomes for youth with special health needs require a successful transition, and a successful transition requires that families and youth with special health needs feel adequately prepared for the actual transition with the young adult successfully integrated into adult health care practices.

There is a lack of adult clinicians who will accept youth with special health needs

Transition planning is not complete until there is a successful transfer to adult clinicians and ongoing established care. National surveys of pediatric clinicians have highlighted the lack of adult clinicians available for youth with pediatric-onset conditions (White & Cooley, 2018). This is a systems-level issue that affects the ability of YSHN to receive the care they need as they transition to adulthood. In Minnesota, a lack of adult health care clinicians available to care for young adults with complex medical needs remains a major barrier to successful transition. Key informant interviews conducted with families repeatedly referred to this barrier. One mother reflected:

There are limited physicians in any field who are prepared to take on the care of an adult (with a pediatric-onset disability). There is not an equivalent to the pediatric providers for children with complex care for developmental disabilities, especially outside the metro area. People who live outstate must travel to find care, which is very limited at best. This experience reflected the broader clinic and system barriers shared by a medical provider, who stated that at the health care practice and system level, as well as at the state and broader systems level, there is not support for clinicians to as they transition patients with medical complexity.

Primary and specialty care providers that are willing to integrate young adults into their practice are identified usually by individual, one to one outreach by a provider and/or by parents. A list of potential providers is typically shared informally through health care providers and families word of mouth. Providers and families 'are on their own' in identifying and interviewing potential adult providers; obtaining information about their interests, skills and comfort level, insurance coverage, hospital privileges, specialists and if their practice is open and accepting new patients. Contributing to the difficulty experienced in finding adult clinicians to care for youth or adults with pediatric-onset conditions is the lack of a centralized listing of providers who will accept these patients. A proactive identification of adult primary and

specialty providers is needed for youth with special health needs with pediatric consultation to ensure continuity of care.

Parents in Minnesota have also reported difficulty in working with hospitals during the transition to adulthood. During a key informant interview, a parent shared:

Hospitals do not have floors or units for these kids who reach 18 years old. I know that in our health system, once my son reaches age 18 he is no longer allowed to be on the pediatric unit. I understand why this is no longer appropriate. At the same time, he is not appropriate to be on an adult general medicine floor. It is inappropriate for my son to be roomed with an older adult, even if he were a typically developing child. Additionally, the staff on these floors are not prepared to care for a young adult with developmental disabilities...There needs to be units for transitional aged people of all abilities, but especially for those with special health needs.

These barriers create a sense of vulnerability for families.

A parent of a child with medically complex needs described this vulnerability, reflecting on her daughter's primary care provider, she stated,

[His] heart was in the right place as he worked on a transition team... We need to replace over 20 medical professionals, in hopefully one hospital, and all that take our insurance plan. It is a nightmare that I feel is not understood by her pediatric or adult team. I also have to work so I can pay the bills, and after balancing all of that, I'm exhausted so this change is extremely hard. We are leaving a team of 23 medical professionals that know and care for us in a family-centered way, going to adult care where family-centered is NOT their first goal in my experience to date.

The confidence in the competency of our team is not something I take lightly, the feeling that they care and go the extra mile is gone now which has become very stressful for me as a parent. I truly feel I have been dismissed after 20 years of working to save her life. It is like starting all over with doctors that have never seen the disease because my child outlived all expectations. Several of the doctors suggested would not take us because of the complexity of her condition.

As these Minnesota parents' experiences demonstrate, the actual completion point of transition for youth with complex care needs is, too frequently, non-existent. Without adult clinicians willing and capable to accept care of medically complex youth, families and youth with complex care needs are left without adequate health care services.

Systems-level barriers prevent families and clinicians from being able to successfully complete transition

While there are individual-level barriers that prevent youth from being able to transition successfully to adulthood, there are also systems-level barriers experienced by clinicians and families. In their clinical report on transition to adult health care, White and Cooley (2018) describe systems-level barriers to transition as experienced by youth and families and physicians. Besides the lack of adult clinicians that will accept youth/young adults with

pediatric-onset conditions other barriers include the lack of guidelines and protocols between pediatric and adult systems. Most delivery systems are not using a structured or coordinated transition processes. This is confounded by inadequate communication between clinicians; sharing of information, use of a medical summary, identifying priorities and follow-up. Consultation and communication between providers is challenged by time and lack of reimbursement. The extra time and cost can be disincentives that influence provider's behavior and discourage them from providing care for youth with chronic conditions. Lack of interoperability of various electronic medical record (EMR) systems in pediatric-sending and adult-receiving practices is problematic. In key informant interviews, families reported that their youth may have files in three or more different EMR systems. Adult practices provide varying levels of care coordination supports: differences in staffing and knowledge about community resources for young adults with chronic conditions. Gaps or loss of insurance coverage among young adults, including a lack of adult providers accepting Medicaid, limit access to continuity of care.

Qualitative data collected through key informant interviews similarly points to these barriers within Minnesota families' experiences with health care transition. A parent of a teenager with special health needs shared:

Our experience is... that each of my child's specialist are part of their own care coordination team and this is not centralized in any way. The pediatrician has a care coordinator; the neurologist has a care coordinator; the physiatrist has their own care coordinator; etc., even within the same health system. If providers are in different systems it becomes infinitely more complicated.

Another mother reflected:

There needs to be a way to coordinate the care for one person and create a team and holistic approach to help transition from pediatric to adult health care models.

Recommendations

As this quantitative and qualitative data illustrate, Minnesota youth with special health needs, as a whole, do not experience an organized, coordinated health care transition. Typically, we encourage families of children or youth with special health needs to learn to navigate the complex system of care their children and youth require. Here, however, we recommend that families not be taught to navigate a broken system, but that instead the system work for families. These transition-focused recommendations are implementable and optimize short and long-term health outcomes for youth with special health needs.

Improve data systems for better evaluation and measurement of health care transition

Better evaluation and improvement of processes that promote successful health care transition require improvements in data systems. Comprehensive evaluation data requires better quality

data, more state-level data, and more data on the outcomes of transition, which includes transition completion.

Current transition measures focus on the transition process, but not on its outcome in adulthood. The National Survey of Children's Health measures the individual components of transition among children age 12-17, but there are no outcomes to demonstrate if the child did in fact transition to an adult provider or to describe the quality of the transition process.

A stronger base of evidence for health care transitions requires that researchers:

- Examine transition outcomes from a population health lens; in terms of the experience of youth and families; healthcare utilization; and cost savings.
- Study how health care transitions impact the long-term outcomes of young adults.
- Recommend that national health surveys include health care transition questions for young adults.

Establish Minnesota cross-sector health care transition coalition

There is a strong need to establish a cross-sector Health Care Transition Coalition to address multiple, complex system issues and lead transformational change in Minnesota. This addresses multiple barriers; for example, clinicians gain knowledge of other providers' interests and skills in adolescent and young adult health and whose practice is able to accept young adults with special health care needs; allows for jointly designed and delivered transition care that recognizes the unique needs of young adults with special health needs; and, addresses and solves actual issues currently faced by Minnesota families with transition age youth. This coalition should include pediatric and adult emergency room physicians, hospitalists and specialists, payers, young adults and families, care coordinators, community based organizations and interested leaders committed to improvement of transition and care integration, including issues with electronic medical record communication.

Build skills and knowledge in youth to advocate for themselves

A successful transition for all youth, but especially those with special health needs requires gaining the knowledge and skills needed to sustain health and wellness. They are more likely to stay well when they understand their health needs and have been trained and supported to work with their health care team. Clinicians and families can assist youth as they transition to adult care through active recognition of increasing youth capacity to manage their own care as they advance through adolescence. Recognizing and responding to the diversity among youth, young adults and their families is essential to the transition process. This diversity may include, but is not limited to, differences in culture, race, ethnicity, languages spoken, intellectual abilities, gender, sexual orientation, and age.

Health systems and clinics must adopt clearly written policies that formalize developmentally and culturally appropriate methods to teach youth health care self-management through skill-building and self-advocacy.

Increase education and training opportunities for health care providers

A major barrier to health care transition reported by health care providers, including care coordinators, is the lack of knowledge related to pediatric-onset conditions, unique behavioral, developmental and psychosocial needs of young adults, difficulties in collaboration with other clinicians who serve adolescents with pediatric-onset conditions or youth with special health needs, and lack of partnership with caregivers of adolescents/adults. Training opportunities must be promoted that:

- Promote best practices in health care transition, such as the *Six Core Elements of Health Care Transition*.
- Meet Continuing Medical Education (CME) requirements so clinicians receive credit for trainings.
- Include multiple modalities, like online learning modules and in-person trainings.
- Build capacity of future clinicians during residency and sub-specialty trainings, which include joint pediatric and adult sessions.

Address gaps in the current infrastructure

Infrastructure-level gaps contribute to challenges experienced by health care providers in helping youth with special health needs transition to adult health care. Current payment structures do not promote innovation in improving health care transition. Payment structures should be developed that:

- Compensate health systems and primary care providers for implementing health care transition activities, such as using transition-specific payment codes.
- Encourage partnerships or collaboration between providers, such as paying for pediatric providers to provide consultation to adult providers on pediatric-onset conditions.
- Providing performance-based incentives when youth are successfully prepared and transferred to adult providers (Develop a transition-focused quality measure to determine eligibility for the performance-based incentive).

System-level process recommendations to improve transition for youth with special health needs include:

- Integration of health care transition processes into routine, preventive well child visits starting at age 12.
- Inclusion of transition process documentation into electronic medical records.
- Promotion of service continuity for youth across child and adult service systems; for example, across systems of education, social services, employment and independent living. Opportunities to support future planning and development include vocational training, post-secondary education, and careers, finding stable housing, accessing health care and financial benefits.
- Collaboration with Minnesota Health Care Homes to recognize unique care coordination needs of youth with special needs.

Conclusion

Minnesota youth with special health needs and their families experience a complex transition from childhood to adulthood as they advance through adolescence alongside chronic condition or disease management. Successful health care transition for these youth lays the groundwork for successful, lifelong positive health outcomes.

Improving transition from pediatric to adult health care is a national priority, a medical home standard, and a meaningful use requirement for electronic health records. This paper addresses the importance of an organized, coordinated health care transition through the presentation of research and data on the needs of youth with special health needs and their families during this critical adolescent stage. Recognition of the relationship between transition and positive adult health outcomes and the manner in which a lack of transition planning contributes to health disparities throughout adulthood, necessitates action to improve the transition experience for Minnesota families and their youth with special health needs. This paper's transition-focused recommendations, which employ a multi-pronged approach to the planning, transferring and integration into adult care of young adults with special health needs, can optimize short and long-term health outcomes for youth with special health needs.

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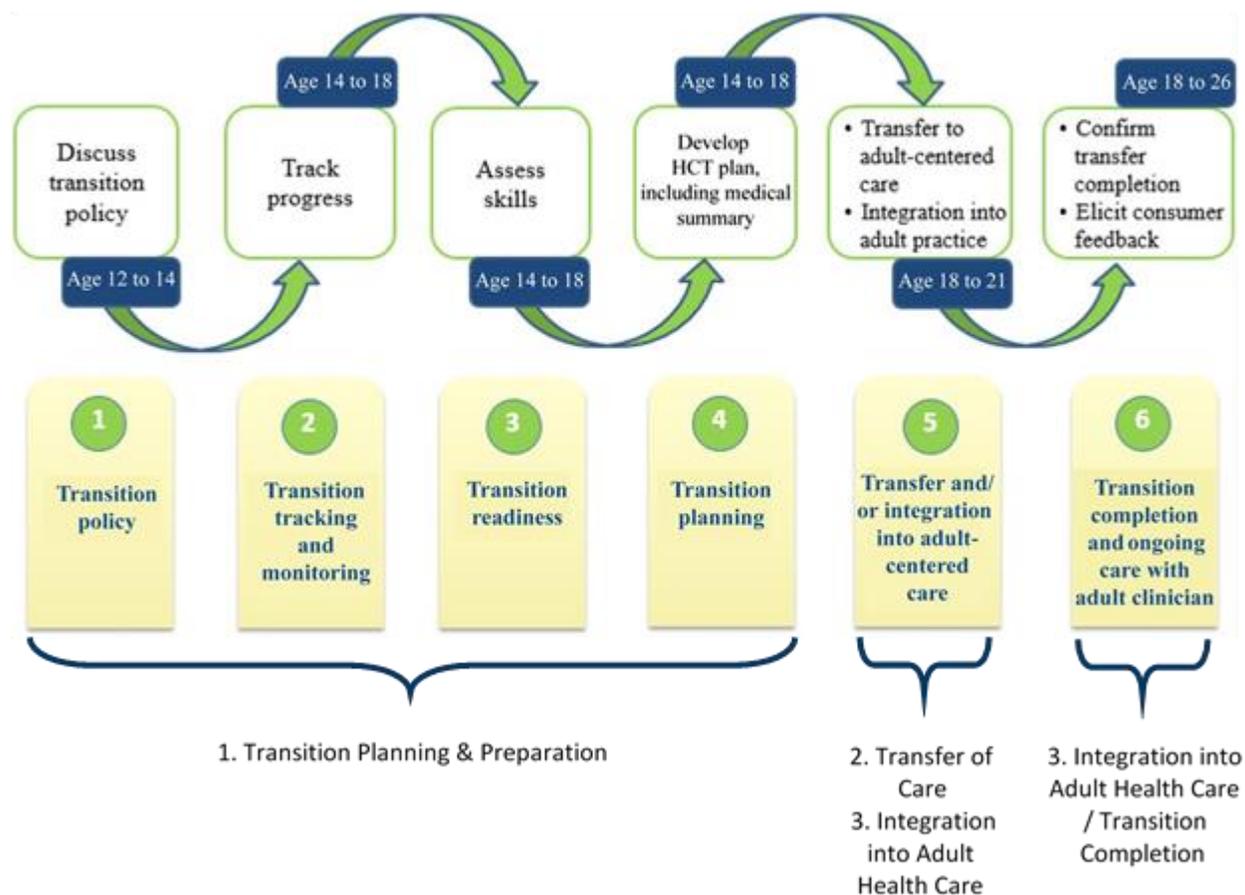
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Appendix A: Six Core Elements of Transition

This paper asserts that health care transition is comprised of three phases: (1) transition planning and preparation, (2) transfer of care, and (3) integration into adult health care/transition completion. In White and Cooley (2018), they further break down these three phases into six core elements of transition. Figure 4 describes these six core elements and provides a timeline for introducing the elements.

Figure 4: Timeline for Introducing the Six Core Elements of Transition

Source: White & Cooley, 2018



As shown in the figure, the six elements of transition are as follows:

1. *Transition Policy:* In conjunction with families, the clinic develops a transition policy. During this phase, staff is educated on the policy. The transition policy should be discussed with the youth and families between ages 12-14 years.
2. *Transition Tracking and Monitoring:* Consists of establishing a process for identification and tracking of youth who are in the transition period, and tracking of youth transition steps, ideally in an electronic health record. Occurs between ages 14-18 years.
3. *Transition Readiness:* Consists of periodic check-in on transition progress, as well as joint development (between adolescent and provider) during transition. Occurs between ages 14-18 years.

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4. *Transition Planning*: The Health Care Transition plan is written, assessments of needs are recorded, readiness for transition is continually assessed, and medical summaries are recorded. Occurs between ages 14-18 years.
5. *Transfer and/or Integration into Adult-Centered Care*: Consists of the actual transfer to adult-centered care and integration into adult practice.
6. *Transition Completion and Ongoing Care with Adult Clinician*: Completes the transition process, with confirmation of transition and feedback from the now adult patient.

Appendix B: Data Tables from Figures

Youth with Special Health Needs Who Receive Supports to Transition to Adult Health Care, Minnesota (Data from Figure 1)

Component	Percent
OVERALL: Received supports needed for health care transition	23.3%
Component 1: Time alone with health care provider	49.2%
Component 2: Actively worked with youth to manage care transition	72.9%
Component 3: Discussed shift to providers who treat adults	18.6%

Average Scores for Transition Elements for Clinics Surveyed (Data from Figure 2)

Transition Element	Family Medicine Average Score	Pediatrics Average Score
Transition Policy	1.6	2.1
Transition Tracking & Monitoring	1.2	1.4
Transition Readiness	1.8	2.8
Transition Planning	1.8	1.4
Transfer of Care	2.2	1.9
Transfer Completion	1.0	1.6
Youth/Family Feedback	1.0	1.0
Youth/Family Leadership	1.2	1.1

Health Care Transition Activities Experienced by Youth with Special Health Needs, Minnesota (Data from Figure 3)

Transition Activity	Percent
Doctor/health care provider actively worked with youth to think about and plan their future	45.1%
Doctor/health care provider worked with child to make positive choices about their health	88.4%
Youth has an up-to-date written plan to meet specific health goals and needs	14.8%
Doctor discussed future insurance needs	50.2%