2008

INTERDISCIPLINARY TRANSITION CONFERENCE REPORT:
Building an Interdisciplinary Research Agenda to Enhance Quality of Life and Transition to Adulthood for Youth with Chronic Health Conditions

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1. The Conference:

What we did

The Center for Children with Special Health Care Needs (CSHCN) at the University of Minnesota’s School of Nursing and the Minnesota Children with Special Health Needs program (MCSHN) at the Minnesota Department of Health convened a conference, “Building an Interdisciplinary Research Agenda to Enhance Quality of Life and Transition to Adulthood for Youth with Chronic Health Conditions,” on Friday, January 18, 2008 at the McNamara Alumni Center at the University of Minnesota.

What we hoped to accomplish

The goals of the conference were three-fold:

- Identify health related-transition issues and research topics that need to be addressed from an interdisciplinary, systems perspective.
- Develop a cadre of interdisciplinary researchers and community partners who are committed to conducting research to improve the quality of services and the quality of life for youth with chronic conditions and their families.
- Create an interdisciplinary transition research agenda.

This working conference brought together health professionals, educators, parents, policymakers, human service providers and young adults to focus on transition issues facing adolescents with chronic conditions.
2. Conference Presentation Highlights

What we heard

Chronic Illness and Disability in Children and Adolescents: Implications for Transition

Key Note Speaker: Judith S. Palfrey, MD
T. Berry Brazelton Professor of Pediatrics, Harvard Medical School
Professor, Harvard School of Public Health
Chief, Division of General Pediatrics, Children's Hospital Boston
Boston, Massachusetts

Why talk about the need for interdisciplinary research on the transitions of teenagers with chronic conditions? Because, simply put, the notion of chronic illness and disability for children and youth is changing.

During the first 60 years of the last decade there were high rates of infant mortality. Children were affected by widespread epidemics—there were 21,000 new cases of polio in 1952, alone. Chronic illnesses and congenital anomalies had few successful interventions or cures. Children who survived typically received long-term care in institutions.

During the 1960s, 1970s and 1980s, vaccines and antibiotics protected children and youth from many diseases. Polio in the United States was virtually eliminated, as were diphtheria and smallpox. High-risk infants received neonatal care; children born with physical anomalies were helped through surgery. Scientists began to understand disease states, and subspecialties such as neurology and cardiology found homes in pediatrics. Families began to demand that their loved ones be deinstitutionalized and that their civil rights be respected.

By 1976, children with disabilities were guaranteed the right to a free education.

During the last 20 years of the 20th century, advancements in medical science and neonatal intensive care interventions resulted in decreasing infant mortality and morbidity among premature infants. Treatments for managing emerging epidemics, like pediatric HIV and AIDS, were developed. Technological advances provided assistance to a broad range of children who are now able to live at home and be actively involved in school and community activities.

This first decade of the 21st century heralds the emergence of childhood chronic conditions that have their roots in lifestyle, environmental and technological changes.

Significant increases in the prevalence of asthma, ADHD, obesity, and Type II diabetes have been reported.

Increased prevalence and survival rates for children and youth with chronic illness and disability also impact health, education and employment environments.

Adolescents with disabilities and chronic illness utilize a substantial proportion of in-patient services.

♦ Health care expenditures for children and youth with chronic health conditions are high — asthma costs for adolescents are close to $1 billion.
♦ Youth ages 14 – 20 years make up 42% of Med-
icaid insurance hospitalization costs— some $968 million.

♦ 28% of youth with disabilities left school without a diploma; 44% of those dropped out because of emotional disabilities.

♦ Most youth with chronic conditions have few functional impairments and are reported to be in good health.

♦ 40% of youth with chronic conditions are not working for pay.

To improve the outcomes for these young people we need to develop an interdisciplinary research agenda that:

♦ Raises the expectations for these young people, their families and their communities.

♦ Identifies the underlying societal issues that promote a long-term investment in children and youth with disabilities, and those that disengage and disenfranchise them when they turn 22.

♦ Explores mechanisms that promote the alignment between social services and clinical services.

Improving Transition Services through Integrated Services and Research for Youth with Chronic Health Conditions

Key Note Speaker: Richard N. Roberts, PhD
Professor, Psychology
Director, Early Intervention Research Institute and National Center for Inclusive Community-Integrated Services for Children with Special Health Care Needs (Champions InC.)
Utah State University, Logan, Utah

Meeting transition needs of youth with chronic conditions should reflect the needs of the consumer. Service systems should be family-centered, youth-centered and engage strong youth involvement. Performance measures are needed to evaluate the effectiveness of transition services.

Eleven state-wide projects in Utah, receiving federal funds, uncovered eight issues that interfered with successful transition of youth to adulthood.

1. Transition is perceived as an event, though it is really a process.

2. Children and youth with chronic conditions have little or no experience managing their own health care.

3. There is a disconnect between youth and adult expectations of education and employment opportunities,

4. Youth want to be treated like any young adult without special health care needs.

5. Families tend to be unaware of programs and resources that could help.

6. Pediatric and adult health care professionals
have limited experience communicating and collaborating on transitioning youth to adult services.

7. There is little, if any, coordination among the health care, education, rehabilitation and insurance systems.

8. Health care, education and social services for children and youth are an entitlement; upon reaching age 22; however, a young person must demonstrate eligibility.

Having the right people talking to each other; developing strong relationships and a shared vision; and excellent organization is necessary to address these barriers to successful transition and change the system.

Since the latter part of the twentieth century, we’ve discovered that policy change happens when the stakeholders are at the center of the discussion. Participatory Action Research (PAR) encourages researchers and those who will benefit from the research (families, providers, policy makers) to work together as full partners in all phases of the research. PAR keeps the stakeholders at the center of the discussion.

At its core, PAR is a way to increase understanding of how change in one’s actions or practices can mutually benefit a community. PAR uses a systematic, iterative method of planning, taking action, observing, evaluating (including self-evaluation) and critical reflecting prior to planning the next cycle.

- During Phase 1, a community focus is developed.
- During Phase 2, baseline data is collected.
- During Phase 3, action plans are identified.
- During Phase 4, outcomes are measured.

These outcomes inform the community and the process begins again.

The actions have a set goal of addressing an identified problem, for example, improving the transition of youth with chronic illnesses and disabilities into adult life. This collaborative method tests new ideas and implements action for change. How will we measure success? We will see:

- Improved or sustained health status over time.
- Young people and their families receiving the right services and supports at the right time.
- Healthcare, recreation, and education inclusive of friends and supports.
Youth and Young Adult Panel: Transition Challenges and Recommendations
Branden McBride, High School Student
Cory Stingl, College Student
Courtney Wells, Graduate Student

Three young adults shared their experience with transition. We learned that:

♦ The referral process, if there is one, is often clumsy and ineffective.

♦ Young people with chronic conditions benefit from peer programs and support groups which:
  - Provide opportunities for young people to learn from others who have made a successful transition.
  - Provide opportunities for youth to learn about their conditions.

♦ Some young people with chronic conditions benefit from creating a person-centered plan with specific goals.

♦ Physicians and others need to improve their communication and have a positive attitude, especially during transition. They need to recognize that young people:
  - Have difficulty leaving a provider that they’ve had “forever.”
  - Need to ease into transition.

Care providers may need to give continued support and commitment to the youth who is transitioning. It may take several visits and require ongoing email or phone communication. The students agree that providers may need to:

♦ Assist and encourage children and youth to take on responsibilities and manage their health care early on (i.e., scheduling appointments).

♦ Address feelings about disability/illness during health care encounters.

♦ Identify mental and emotional health supports and resources.

♦ Encourage youth to have an outlet to talk about chronic illness or disability.

♦ Recognize that families also have special needs when the transition process occurs.
3. Transition Research Agenda Development

What we discussed

The transition issues and research questions identified below clearly underscore the complexity of the transition process for youth with chronic health conditions and their families as they interact with multiple systems. Measurable outcomes that are the best indicators of successful transition need to be identified. Furthermore, measures must be developmentally appropriate and sensitive to changes in the chronic health condition and systems of care. Research teams need to consider transition issues and barriers related to the type of condition, the developmental stage of the child as well as the timing of interventions. Longitudinal research studies that follow youth with chronic health conditions as they transition (e.g., from pediatric to adult health care; high school to vocational education, college and/or work; and home to independent living) are needed to identify best practices and turning points that call for new interventions and systems change.

The research topics identified by conference participants were organized into the following categories:

- Youth-focused
- Community-focused
- Systems-focused
- Professional Development and Training

Interdisciplinary research must be youth-focused and:

1. Address chronic condition factors:
   - What is needed for youth with chronic conditions to transition to adulthood successfully (timing/outcomes/resource use)?
   - Which chronic condition factors are associated with social competencies?
   - What influence do chronic condition factors have on transition and quality of life?
   - How do characteristics of the condition influence what is needed for an effective transition?

2. Promote healthy youth development:
   - How could the principles of healthy youth development be incorporated more effectively into transition planning?
   - What are the best ways to promote the development of:
     - Self-care skills (independent of parents)
     - Social skills
   - What are the key relationship skills needed for a successful transition?
   - Which relationships and types of relationships promote healthy development during transitions in different arenas (e.g., family, peer, school, health care, disability related, recreational, work)?
   - What skills do students/youth need to help them explain their disability and transition
needs (e.g., to peers, educators and health care professionals, employers)? Who helps them to develop these skills? What resources are needed?

- What are effective ways to prevent depressive symptoms and improve quality of life for youth with chronic conditions?
- Which individual and family capacities promote independence?

3. Acknowledge supports needed for youth and families:

- What longitudinal transition studies and measures are needed to better understand the supports needed at specific turning points and transitions for youth with chronic conditions?
- What are the key supports in a youth’s life that hinder or support transition?
- How does transition happen for children and youth who are not in special education? Who teaches them about accommodations, adult problem solving, medical care responsibilities, adult roles, etc.?
- What interventions are needed to smooth transitions for youth and their families?
- What needs to be done to ensure that youth and families have resources and know the tools that are available to them?
- What is the optimal approach to creating and maintaining a meaningful care plan to assist individuals and caregivers with transition and beyond?

4. Incorporate peer support:

- How do we develop and sustain peer-peer support initiatives?
- How do we help adolescents and young adults in transition connect with each other?
- How do interactive peer groups (either in person or virtual) improve the transition process?
- What are meaningful opportunities/programs for young adults (age 22+) with severe disabilities (physically/cognitively)?

5. Include supportive technology

How can technology be used to create virtual support networks?

- How can we use emerging technology (e.g., Secondlife, www.secondlife.com, a 3D virtual world) to help adolescents explore transition to adult issues?
- What role does electronic communication (email, chat, video conferencing, social networking websites, health websites) play in facilitating transition?

Interdisciplinary research must be community focused and:

1. Address Heath Disparities:

- How do disparities (e.g., cultural, ethnic/racial, economic, geographic) affect transitions?
- What impact do culture and poverty have on successful transition?
What are the variations and challenges for youth and the families from minority and immigrant communities in health service access, health service outcomes, and health service knowledge?

How do we reach adolescents who are homeless or highly mobile and have a chronic condition?

How do issues of isolation, lack of providers, lack of employment, transportation, poverty, and peer support influence transition for youth in rural areas?

2. Ensure culturally appropriate systems and interventions:

How can cultural values become part of the research agenda?

What are effective ways to:

- Involve families and youth in the design of culturally appropriate services and interventions?
- Include grassroots cultural health networks in developing solutions to transition issues?
- Engage representation from more culturally diverse communities in cross-agency collaboration efforts in MN?
- Implement culturally appropriate youth/family-centered planning/goal setting to promote healthy development?

Interdisciplinary research must be systems-focused and:

1. Promote seamless, coordinated systems:

What would a comprehensive, coordinated commitment to transition in health, education, human services, and employment look like?

What impact would system coordination (healthcare, education, social services) have on transition outcomes?

As we work toward systems change, how do we ensure that the “power” to push for that change focuses on the family and community level?

What evidence can we provide that outcomes differ when family-professional partnerships work?

How do we create greater seamlessness between systems for youth in transition?

What incentives can be created to encourage systems (family, education, medical) to work together to simplify care delivery?

How do we integrate data among multiple health, education, government, and social agencies so it can easily be shared during transition?

How does a system of care and services successfully address individual differences and preferences?

What array of services contributes to the successful attainment of personal goals related to the transition from adolescence to adulthood?
How can we create better bridges from the services and supports received by youth and those needed for adult roles and activities?

What interagency strategies/tools are needed that could be used by students, families, professionals to improve collaboration?

What are effective ways to address legal barriers to transition (related to employment, insurance, etc.)?

**2. Influence systems change through translational research:**

How do we better link research to practice to create systems change?

How do we translate research and what we know benefits families into practical policies and supports?

**3. Address economic and financial issues:**

What are the cost benefits of reducing barriers to service coordination and providing benefits planning for youth with complex chronic health conditions?

How can the financing system be changed to promote growth and development of young people as they move into adulthood?

What costs or incentives need to be in place to create effective systems change?

How do we motivate major payers to fund transition interventions?

What financial incentives for health providers are needed to serve children with special health care needs in transition?

What are the funding constraints that prevent successful transitions to adulthood (e.g., employment, post-secondary education)?

**4. Understand the impact of school-based transition issues:**

What role does the school play in the transition of students with a chronic health condition?

What key in-school experiences contribute the most to successful outcomes in adulthood? What key in-school experiences are missing?

What transition resources are available and needed by school nurses?

How does a medical/health care professional presence at IEP’s influence the content, process and outcomes of IEP’s with regard to transition?

**5. Understand the impact of health care based transition issues:**

How do psychosocial issues impact or hinder treatment of chronic conditions during transition?

How can youth be best empowered to take ownership of their health care?

What are the best ways to engage individual health care practitioners in improving transition services for children and youth with special health care needs (CYSHCN)?

When is the adult health care community a safe
place for care for persons with health conditions originating in childhood? Does the type of health condition matter?

- How can we overcome the “falling off the cliff” motif adolescents face when transitioning to adult medicine?
- What are effective ways to provide continuity of care to maintain trusting relationships during health care transitions?
- What are key components of successful transition of medical care from pediatric to adult health care?
- What measures or procedures are needed to facilitate transition from pediatric to adult health care?
- What steps work best for youth to determine where to go for adult care?
- Is “holistic” attention to physical and mental health care possible? What systems changes are needed?

Teach adolescents how to advocate for themselves.

- Educate the medical community (e.g., pediatricians, Internists, family practitioners) about transition issues?
- Inform pediatric and adult health professionals how to transition youth with chronic health conditions from pediatric to adult services.

**Interdisciplinary research must identify professional development and training needs to help understand:**

1. What are the best practices for developing and implementing training curricula for parents, interdisciplinary teams and youth around emerging adulthood transition issues?

2. What are the most effective ways to:

- Educate the adolescent and their health care providers on transition of care?
4. Research Action Plan Development

How we completed our work

Conference participants were divided into four interdisciplinary working groups that included parent and youth representatives. Individuals within each group first identified two high priority interdisciplinary related transition research topics. Next, group members worked together to organize transition topics into major research themes. Then, each working group member had an opportunity to vote on the top 3 highest priority interdisciplinary transition research topics. Each group next worked on developing action plans to address two of the top priority topics.

See Appendix A for a copy of the Research Action Planning Tool that interdisciplinary teams can use to address transition research topics identified in this conference report.

Who we want to thank

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**Transition Research Topic #1:** (list topic)

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<th>Resources Needed</th>
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