

CHRONIC NEGLECT BY OUR HEALTH CARE SYSTEM OF CHILDREN & YOUNG ADULTS WITH CHRONIC MEDICAL CONDITIONS & DISABILITIES

This report summarizes findings from a meta-analysis on the state of the U.S. health care system for our nation's most vulnerable population – children & young adults with chronic medical conditions and disabilities. These disturbing findings reveal a widespread health care crisis created by inadequate public-private sector attention and strongly indicate a need for a national strategy leading to policy reform and the commitment for research funding to better address this population's health care needs.

Delivering quality health care for “children with special health care needs” must be a priority.

*Priority Areas for National Action:
Transforming Health Care Quality – Institute of Medicine*

Chronic Medical Conditions and Disabilities are a Growing Family Crisis

- ◆ Over 10 million children and 4.5 million young adults have chronic medical conditions and disabilities (CMCD).^{1,2}
- ◆ 8% of children up to age 5 and 16% of children aged 12-17 years have chronic medical conditions.³
- ◆ One in five American households has at least one child with a chronic medical condition or disability.⁴

Poor Quality Health Care Leads to Incremental Suffering - Even in Families with Private Insurance

- ◆ Children with CMCD with private insurance only get one-half of the needed care, leading to avoidable emergency room visits, hospitalizations, morbidity and mortality.⁵
- ◆ Four out of five children with mental health problems do not get evaluated or treated.⁶
- ◆ Although Children & Young Adults with CMCD are at heightened risk for medical errors, little research on reducing errors has focused specifically on this population.⁷

There is Poor Access to Coordinated Care and Community-Based Services

- ◆ Less than half of Children with CMCD have a ‘Medical Home’ (meaning they lack a system of continual, coordinated medical care).⁸
- ◆ Only 20% of Children with CMCD up to age 11 and 13% of teens aged 12-17 years access community-based services.⁹
- ◆ Federal criteria for what goes into a community-based system of services have not been broadly adopted.¹⁰

Transitioning to Adulthood Means Confronting More Health Service Challenges

- ◆ Every year, 600,000 Children with CMCD reach adulthood, yet only 16% have a plan to guide their transition to adult health care.^{11,12}
- ◆ More than one-half of Young Adults with CMCD lack a primary source of care.¹³
- ◆ Over two-thirds of Young Adults with CMCD delay or miss needed care due to cost.¹⁴

Impact on Families, Society and the Economy

- ◆ About 40% of parents stop working or reduce work hours to care for their Children with CMCD.¹⁵
- ◆ Only 40% of Young Adults with CMCD can get private insurance and one in four are uninsured.¹⁶
- ◆ Poor care leads to poor health and functional disabilities and means that Young Adults with CMCD are three times more likely than healthy peers to earn under \$15,000/year.¹⁷

The individual, family, and societal health and loss of productivity costs are staggering . . .



Physician-Parent Caregivers

Working Together to Obtain Quality Health Care for Kids with Chronic Conditions & Disabilities

WHAT MUST WE DO TO KEEP OUR CHILDREN & YOUNG ADULTS WITH CHRONIC MEDICAL CONDITIONS & DISABILITIES HEALTHY?

Following are a list of actions for improving the inadequate level of health care services and support for the 15 million Children & Young Adults with Chronic Medical Conditions & Disabilities in the United States.

IMPLEMENT a National Strategy as a National Priority

- ◆ Key Federal and State agencies must be directed to work together to streamline access and integrate existing programs/policies to ensure that all Children & Young Adults with Chronic Medical Conditions and Disabilities (CMCD) have access to quality health care and necessary services and supports.
- ◆ Collaboration and public/private partnerships should be supported to enable the development of programs and policies that promote proven approaches to health care (e.g., Medical Homes) and broaden access to community-based disease management programs, provide Young Adults with CMCD with Health Care Transition services, and increase reimbursement for the services that Children & Young Adults with CMCD need.
- ◆ A comprehensive approach needs to be adopted that ensures Young Adults with CMCD transition seamlessly to adult health care and self-management, obtain post-secondary education and training, secure meaningful employment, live independently, and fully participate in their communities.

AMEND AND IMPROVE Existing Policies

- ◆ Modify eligibility and funding to assure all Children & Young Adults with CMCD have adequate health care coverage. Raise or remove age limits for continued health care coverage through Medicaid, SCHIP, and private insurance.
- ◆ Extend wrap-around services to all Children & Young Adults with CMCD regardless of whether they are covered by public or private insurance.
- ◆ Mandate Medical Homes for all Children & Young Adults with CMCD enrolled in Medicaid or SCHIP.
- ◆ Review and modify policies governing child and young adult education so that the needs specific to chronic medical conditions, participation by health care professionals, and Health Care Transition plans and supports are appropriately addressed.

INVEST in Research

- ◆ Little research has been done on formal definitions, characteristics and needs of Children & Young Adults with CMCD. Building on recommendations of the *Quality Chasm Series and Future of Disability Reports*, the Institute of Medicine should conduct in-depth analyses and develop recommendations regarding Quality Health Care and related services for Children & Young Adults with CMCD.
- ◆ Identify challenges Young Adults with CMCD face in getting health care and discover best practices to support them through vocational/higher education and link them with meaningful employment.
- ◆ Look beyond the United States and identify and study successful models used in other nations to assure Children & Young Adults with CMCD receive needed services and supports, are employed, and are fully included in their communities.

These children and young adults need our help – please visit www.ppc-inc.org to learn more.

Our health care system has abandoned these vulnerable children and young adults – with your help, we can make a difference in their lives. Please visit www.ppc-inc.org or write to us at info@ppc-inc.org today to learn how even a small time commitment or modest donation can make a big difference.

- Prepared by Physician-Parent Caregivers 2009



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