

# QUALITY HEALTH CARE FOR CHILDREN & YOUNG ADULTS WITH CHRONIC MEDICAL CONDITIONS & DISABILITIES IS CRITICAL TO OUR NATION'S HEALTH

## THE FACTS

### A Growing Problem:

- ◆ The number of children with chronic medical conditions & disabilities has increased over the past 4 decades to over 10 million children and 4.5 million young adults.<sup>i,ii,iii</sup>
- ◆ The frequency of chronic medical conditions increases with age, going from 8% of children up to age 5 to 16% of 12-17 year olds<sup>4</sup> to 45% of adults.<sup>5</sup> Youth and young adults have not been adequately studied.<sup>6,7,8</sup>
- ◆ One in five (8.8 million) American households includes at least one C-<sup>9</sup>
- ◆ The tripling of obesity since 1980 puts another 25 million overweight and obese children at risk for chronic conditions.<sup>10</sup>

### Poor Quality Health Care:

- ◆ Insurance, a critical first step, does not ensure access to *quality* health care.<sup>11</sup>
  - ◆ One study of insured households revealed that C-CMCD receive only half of needed care; this risks avoidable emergency room visits, hospitalizations, and unnecessary morbidity and mortality.<sup>12</sup>
  - ◆ Four out of five children with mental health problems do not get evaluated or treated.<sup>13</sup>
  - ◆ C-CMCD & YA-CMCD often lack monitoring and interventions for common coexisting conditions, such as anxiety, depression, and suicide risk.<sup>14,15</sup>
  - ◆ Medical Errors kill 98,000 adults and harm countless more.<sup>16</sup> Although C-CMCD are at heightened risk for medical errors, little research has been focused on them.<sup>17</sup>
  - ◆ The American Academy of Pediatrics and Department of Health and Human Services recommend all C-CMCD & YA-CMCD receive continuous comprehensive, patient-centered care in a Medical Home.<sup>18</sup> One recent study reports only 47% of C-CMCD have a Medical Home.<sup>19</sup>
- ◆ Some Federal criteria have been promulgated for a community-based system of services for C-CMCD, but just 20% of C-CMCD up to age 11 and only 13% of teens aged 12-17 years access such care.<sup>20</sup>
  - ◆ Quality health care for “children with special health care needs” was identified as a priority by the Institute of Medicine.<sup>21</sup>

### Transitioning to Adulthood:

- ◆ Every year, 600,000 YA-CMCD reach adulthood.<sup>22</sup>
- ◆ Just 16% of youth report having a plan to guide their transition to adult health care<sup>23</sup> not withstanding a Healthy People 2010 goal for all C-CMCD to successfully transition to adulthood.<sup>24</sup>
- ◆ YA-CMCD struggle to find adult physicians to care for their childhood onset conditions.<sup>25,26</sup>
- ◆ About 54% of YA-CMCD lack a usual source of care and over two-thirds delay or miss needed care due to cost.<sup>27</sup>

### Impacting Society and the Economy:

- ◆ YA-CMCD often lose coverage as they age out of SCHIP, Medicaid and private insurance.<sup>28</sup>
- ◆ Just 40% of YA-CMCD have private insurance and 26% are uninsured. Only 54% attend college or work, usual prerequisites for private insurance.<sup>29</sup>
- ◆ YA-CMCD are 3 times more likely than healthy peers to earn under \$15,000/year.<sup>30</sup>
- ◆ For C-CMCD, 27% of parents must cut back on work and another 13% stop working to help their children.<sup>31</sup>
- ◆ Siblings and parents of C-CMCD are at risk for health problems.<sup>32,33,34</sup> Many marriages dissolve and families fall apart.<sup>35</sup>
- ◆ Quality health care support during and after transition is critical to assure YA-CMCD are healthy and contribute actively to society.

**Key** C-CMCD: children with chronic medical conditions and disabilities from 0 -17 years.  
YA-CMCD: young adults with chronic medical conditions and disabilities from 18-24 years.

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



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

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

### IMPLEMENT a National Strategy.

Working to ensure quality health care for C-CMCD & YA-CMCD and their families should be a national priority.

- ◆ Federal and state agencies serving the many affected subgroups, e.g., children with special health care needs, disabilities, mental health, SCHIP/Medicaid, education, etc., should work together to streamline access and to harmonize programs and policies to service children and families efficiently and effectively and to ensure that C-CMCD do not fall through the cracks.
- ◆ A private/public partnership of Federal and State Governments, the medical community, business community, health care payers, quality improvement organizations, community groups, schools, colleges, families, and youth, and should work collaboratively to develop and implement programs and policies that support quality health care. This may include improved reimbursement for programs, availability of Medical Homes, provision of Health Care Transition services, and access to disease management programs.
- ◆ Strategies need to be developed for YA-CMCD to ensure transition to adult health care, self-management, success in education, continuous meaningful employment, and independent living.
- ◆ Methods should be developed to identify, track, and optimize the health care and wellbeing of C-CMCD & YA-CMCD.

**CHANGE Policy.** Policies need to be developed that target the unique needs of this population. Programs that are supposed to be inclusive require modification in eligibility and funding, e.g., rehabilitative services for all YA-CMCD.

- ◆ We support adequate health care coverage and health care based transition

plans for all C-CMCD & YA-CMCD.

- ◆ Medical Homes and wraparound services should be provided for all C-CMCD & YA-CMCD covered by public/private insurance.
- ◆ We recommend existing policies be reviewed and modified as appropriate to ensure the protection of the rights of individuals with chronic conditions.
- ◆ We recommend that Health Care Transition support, including participation by health care professionals be incorporated into educational policies for C-CMCD & YA-CMCD in schools and colleges.
- ◆ Demonstration programs using innovative approaches, e.g., health games, e-coaching, and patient navigators should be explored for both C-CMCD & YA-CMCD.

**INVEST in Research.** Little research has been done to study the characteristics and needs of this population.

- ◆ Building on the recommendations of the Quality Chasm Series and Future of Disability Report, the Institute of Medicine should conduct a study on Quality Health Care for Children & Young Adults with Chronic Conditions & Disabilities.
- ◆ Universal definitions for C-CMCD & YA-CMCD should be developed to reduce confusion and ensure eligibility/access for programs.
- ◆ Studies of YA-CMCD should identify if and how they get health care and best practices to support them through vocational/higher education and link them with meaningful employment.
- ◆ Methodologies must be developed to monitor Medical Home access, quality, outcomes, and availability of Health Care Transition services and supports.
- ◆ We support in-depth analyses of the quality of health care and related services for C-CMCD & YA-CMCD.
- ◆ The U.S. could benefit from study of successful models in other nations in this arena.

*Prepared by Physician-Parent Caregivers 2009*

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