

Episode 2: CDC's Life Course Model for Children and Young Adults With Chronic Conditions

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Webinar Series Sponsored by AAIDD and AAHD:

**The Unique Role of CDC's Division of Human Development and Disability,
Centers for Disease Control and Prevention**

Webinar Series Overview

❑ Hosted by AAIDD and AAHD

❑ Four-part webinar series

1. CDC's Public Health Approach to Disability
2. **CDC's Life Course Model for Children and Young Adults with Complex Conditions (November 2011)**
3. Differences in Health Status for People with Disabilities
4. CDC's Roadmap for Improving the Health of People with Disabilities

Key Points You Will Hear Today

- ❑ 1 in 5 Americans have a disability**
- ❑ Important among them are children and adults born with complex conditions**
- ❑ The Division of Human Development and Disability is uniquely tasked to improve the health of people living with these conditions across the life course**
- ❑ The Division's ongoing work strives to influence others who also work to ensure successful adult living for people with complex conditions**

**1 IN 5 AMERICANS HAVE A
DISABILITY...AND NOW THEY'RE LIVING
LONGER. WHO'S HELPING THEM ATTAIN
SUCCESSFUL ADULT LIVING?**

The Disability Landscape

- ❑ Globally, there are 1 billion people with disabilities, ~15% of the population (WHO/World Bank, 2011)**
- ❑ In the United States, 54 million people have disabilities (1 in 5 Americans)**
- ❑ A disability limits the function of a person in relation to the environment and other personal factors**
- ❑ People with disabilities are 4 times more likely to report poor health**
- ❑ \$400 billion annually in disability-associated health expenditures in the U.S.**

Population of Interest

❑ **Complex health conditions have:**

- Onset in childhood
- Cannot be cured
- Continue into adulthood
- Involve at least one body system that could have an impact on function and participation.

Needs of this Population

- ❑ Young people with complex health conditions constitute 15-20% of population (CSHCN survey, 2007) and experience disparities in important functional outcomes, like school, employment and independent living arrangements, doing less well than typical children**

- ❑ They also experience wide variation in outcomes**
 - Across conditions
 - Within each condition

Functional Areas Affected by Complex Conditions

- Overall health status
- Self-management of health
- Physical activity/Obesity/Nutritional status
- Emotional well-being
- Employment
- Personal relationships
- Participation in recreation, spiritual and civic activities in community
- Independent living arrangements
 - (Swanson, Peds Clinic NA, 2010)

Children with Complex Conditions

- ❑ Children with complex conditions and their families, have the same aspirations for successful adult living as typical children**
- ❑ More people surviving and living longer**
- ❑ Natural history of many impairments is variable or unclear because:**
 - Only recently have children lived well into adulthood
 - Physical health and functional outcomes have not been documented
 - Impairments may progress or stabilize, depending on the underlying condition

Needs of this Group

- ❑ Adverse outcomes may be mediated through inequity in access to services like:**
 - Health services that prepare for adult life
 - Educational services that prepare for adult employment and learning
 - Parent training and support
 - Health literacy
 - Coordination of health, social and educational services
- ❑ Public health could play a role in monitoring and making changes in provision of these public services**

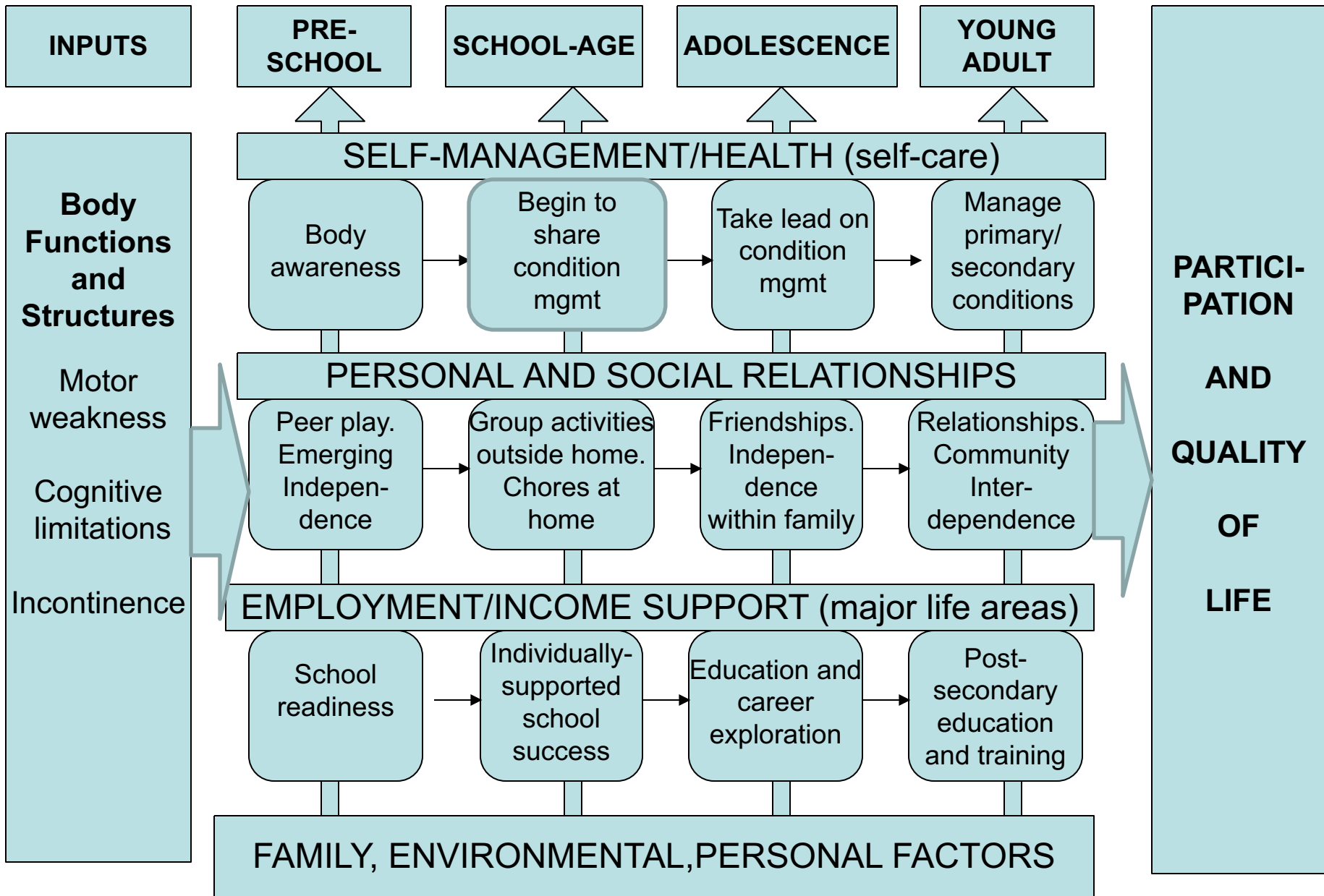
**WE PROMOTE THE HEALTH OF
CHILDREN AND ADULTS WITH
COMPLEX CONDITIONS ACROSS THEIR
LIFE COURSE**

CDC's Division of Human Development and Disability

- ☐ Uniquely tasked to improve the lives of people living with complex conditions such as fragile X, muscular dystrophy and spina bifida**
 - Health across life course: Children and Adults
- ☐ Funding supports DHDD to:**
 - Collect data
 - Conduct research
 - Inform evidence-based programs
- ☐ Bottom Line: Improved quality of life and successful adult living**

LIFE COURSE MODEL

- International Classification of Functioning, Disability and Health (ICF) defines successful adult living as participation in eight domains. Our Life Course Model focuses on three of those domains.**
 - 1. Interpersonal interactions and relationships**
 - 2. Major life areas**
 - 3. Self-care (management)**



LIFE COURSE MODEL

- ❑ A developmental approach is needed to map trajectory to successful adult living
- ❑ The bio-psychosocial model is in play here. Successful adult living is the result of interaction between impairment, personal factors and environment over time (a child's life)
- ❑ Current clinical approaches to developmental progress often focus on activities (e.g., performance on most standardized tests)
- ❑ Focus should shift to measurement of participation (how one fares in the real world)

SPINA BIFIDA LIFE COURSE MODEL WEBSITE

(sbpreparations.org)

☐ 4 time points:

- **Early Childhood**
- **School-Age**
- **Adolescence**
- **Young Adults**

☐ 3 domains:

- **Health / Self-Management**
- **Personal / Social Relationships**
- **Education / Employment / Income Support**

USE TO FAMILIES AND PROFESSIONALS

- ❑ Tracks development in key domains across life course**
- ❑ Focus is on positive outcomes rather than deficits**
- ❑ Prompt families to promote normalization**
- ❑ Prompt professionals to track important variables in domains sometimes overlooked in clinical practice**

**WE GENERATE PUBLIC HEALTH DATA
TO SUPPORT A LIFE COURSE
APPROACH**

Bridging the Gap: Medicine and Public Health

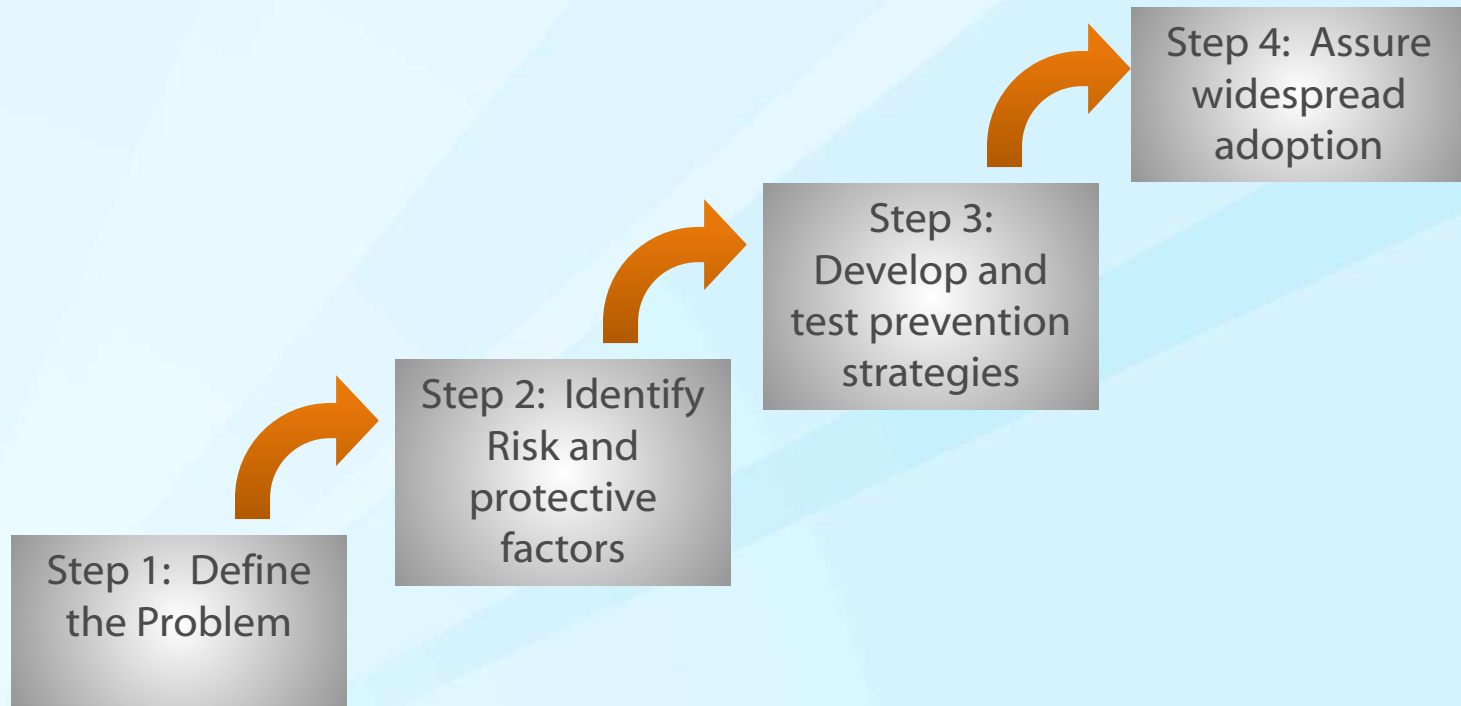
Medicine

**Focus is on individual health
Emphasis on treatments and cures**

Public Health

**Focus is on population health
Emphasis on prevention and
improving health**

The Public Health Approach to Complex, Childhood Conditions



DHDD's Work: Muscular Dystrophy

MD STARnet (Muscular Dystrophy Surveillance Tracking and Research Network)

- Population-based**
- Identify and gather information on all those with Duchenne or Becker muscular dystrophy in five states plus Western New York**
- Details diagnostic timeline, use of genetic testing, clinical signs and symptoms, treatments, and associated conditions**

Findings from MDStarnet

- ❑ **Over 800 people, including 220 representing minority groups**
- ❑ **~60% survival among 20-24 year olds; more people are living with Duchenne/Becker MD as young adults**
- ❑ **First population-based prevalence estimate in the US (1.3-1.8 per 100,000) males 5-24 years**
- ❑ **Diagnostic delay of 2.5 years between first signs and diagnosis. Has not changed in 20 years.**
 - National Task Force for Early Identification of Neuromuscular Disorders
 - American Academy of Pediatrics – guidelines to improve early diagnosis of developmental delays

DHDD's Work: Muscular Dystrophy

Muscular Dystrophy Care Guidelines

- ❑ Guidelines complete for Duchenne muscular dystrophy
- ❑ Guidelines under development in conjunction with the American Academy of Neurology for four additional forms of muscular dystrophy
 - myotonic dystrophy
 - limb-girdle muscular dystrophy
 - facioscapulohumeral muscular dystrophy
 - congenital muscular dystrophy

DHDD's Work: Spina Bifida

National Spina Bifida Multi-site Study

- Clinic-based**
- Documents the care received by children and young adults with spina bifida**
- Measures the results of specific interventions over time (longitudinal)**
- Determines which interventions are associated with positive outcomes**

DHDD's Work: Fragile X Syndrome

National Fragile X Family Survey

☐ Survey of 1250 families affected by fragile X syndrome (FXS) and fragile X-associated disorders. Survey addresses:

- **Diagnosis**
- **Treatments and services**
- **Adult needs and transition to adulthood**
- **Key public health outcomes**

Findings from the Fragile X Family Survey

- ❑ 31% of male children with FXS were obese compared to 18% same-aged peers in the general population**
- ❑ 47% of families reported FXS caused a financial burden**
- ❑ 62% of families reported that parent had to change work hours or stop working**
- ❑ 66% of males with FXS exhibited hyperactivity and 38% exhibited aggressiveness**

**WE CONTINUE TO WORK FOR HEALTHY,
SUCCESSFUL LIVING FOR CHILDREN AND
ADULTS WITH COMPLEX CONDITIONS**

DHDD's Work:

Describe the problem and identify risk and protective factors

Future Projects

☐ South Carolina Study of Adolescents and Young Adults with Rare Conditions

- Cross-conditional (FXS, SB, and MD)
- Linked administrative data sets – describe experience of people 15-25

☐ Spina Bifida Natural History Project

- Testing the school readiness of children with spina bifida as compared to those without the condition
- Unique methodology may apply to other rare disorders

Complex Conditions Current and Future Activities

Need better understanding of:

- Health care costs**
- Economic impact to family**
- Monitor care and patient outcomes**
- Access to health care**
- Quality of life and ability to function**

Complex Conditions Current and Future Activities

Need better understanding of:

- Patient's ability to self-manage**
- Transition from child to adult health care provider**
- Promote healthy lifestyle across the course of their life**
- Evaluate policies supporting access to care, social participation and independence for people with MD**

DHDD's Partners in Public Health

- Families
- Patient advocacy groups
- Professional organizations
- Clinicians
- State and local departments of health
- Government agencies
- Academic institutions

Our Public Health Vision for Complex Conditions

- ❑ Produce data that improves the quality of life for children and adults with complex conditions**
- ❑ Data leads to changes in major service systems, such as health, education and social services**

In Summary...

- ❑ 1 in 5 Americans have a disability**
- ❑ Important among them are children and adults born with complex conditions**
- ❑ The Division of Human Development and Disability is uniquely tasked to improve the health of people living with these conditions across the life course**
- ❑ The Division's ongoing work strives to influence others who also work to ensure successful adult living for people with complex conditions**

QUESTIONS

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