

Bridging the Gap Between Tourette Syndrome and Public Health

Public health can improve the lives of individuals with Tourette Syndrome (TS) and their families, and can help create communities and institutions that support the potential for full, productive living for those affected by TS. Public health emphasizes the prevention of disease and disability, and improves the health and well-being of *populations* rather than individuals. The 10 Essential Services approach is one framework that provides a foundation for any public health activity. This approach emphasizes three areas: assessment (monitor, diagnose and investigate), policy development (inform and educate people, mobilize partnerships, develop policies) and assurance (link people to needed services, assure a competent workforce, evaluate health services) (1). The purpose of this document is to raise awareness of TS as a public health issue, highlight gaps in knowledge and resources that can be addressed by public health, and begin the process of developing public health priorities for TS.

Tourette Syndrome is a neurobehavioral condition characterized by motor and vocal tics (2) that impacts health, education, employment, and family and social relationships. Isolated and transient tics are common among children, affecting up to 20% of the school-age population. Estimates of any tic disorder in childhood range from 2% to 4% (3-7). Prevalence estimates of TS vary widely, ranging from 1 to 30 per 1,000 children, but several recent estimates of TS fall in a narrower range of 3 to 8 per 1,000 children. These recent estimates tend to come from larger, community based samples focused on identifying tics rather than on clinic-based studies or studies focused on multiple conditions (4-6, 8-10). People with TS and other tic disorders have elevated rates of other mental, emotional and behavioral (MEB) conditions. If these conditions are not identified and treated early, people with TS may be at higher risk for long-term negative consequences.

Early identification and appropriate management of tic disorders, including TS, are necessary to limit the health impairments caused by these disorders and associated MEB conditions. Addressing the health needs of those with TS and their families is consistent with a core mission of the Centers for Disease Control and Prevention (CDC):
“...collaborating to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury and disability...”, as well as with the mission of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to: “promote the health of babies, children and adults and enhance the potential for full, productive living.”



Tic severity, the course of tic symptoms, and co-occurring MEB conditions vary widely in individuals with TS. The most common co-occurring conditions include attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder, but depression and other behavioral and anxiety disorders are also common (11, 12). Although some individuals with tic disorders outgrow their tic symptoms by early adulthood, approximately 10%-20% of affected children continue to have clinically meaningful tic symptoms into adulthood. Even when tic severity decreases by early adulthood, unrecognized and untreated co-occurring MEB conditions can have substantial impact throughout the lifespan, preventing individuals from reaching their full potential for a healthy and productive life.

The cost of TS to society is presumed to be substantial. Individuals with TS and other tic disorders use more mental health services and psychotropic medications; have greater need for educational accommodations; and more frequent academic problems and employment difficulties (13-18). Childhood psychological problems are associated with lower educational achievement, an increased likelihood of parents stopping work, and a 20% reduction in income by the time the affected child reaches adulthood (19-21). In addition, tic disorders significantly impact family finances (13, 15). One study of 200 adults in Germany confirmed significant costs associated with TS, including direct costs (e.g. health care costs) and substantial indirect costs associated with lost work (17).

Gaps in Knowledge and Resources that can be Addressed by Public Health

To identify gaps that can be addressed by public health, CDC conducted a literature review and convened an expert panel (see Appendix A) that included neurologists, psychologists, epidemiologists, a psychiatrist, a nurse practitioner in child psychiatry, a parent, and representatives from the Tourette Syndrome Association (TSA). The literature review and expert panel discussions focused on the individual and social burden of TS, the epidemiology of TS and available treatments and interventions for TS. Two broad areas of need were identified. They are:

- I. ***Improved epidemiology of tic disorders, including TS and co-occurring MEBs, is necessary for a better understanding of their magnitude and impact in our society.***
 - a. Improved case definitions and measures of tic disorders, including TS, are needed for use by public health and clinical professionals. Both are necessary to improve the precision of prevalence estimates, highlight differences between less and more impairing forms of TS, and allow for better monitoring of symptoms and functioning over time.
 - b. Improved surveillance, including indicators of severity and timing of symptoms is needed to better document the prevalence and the course of the conditions across the lifespan, including among minority and underserved populations.

- c. Documentation of the burden of tic disorders, including TS and co-occurring MEBs, is needed across multiple domains (e.g. family stress, social competence, education, employment and cost). A better understanding of the burden of TS across the lifespan on the individuals, their families, and society is necessary to inform public policy and help direct the allocation of public health resources.

II. *Efforts to improve the health and well-being of people affected by tic disorders and co-occurring MEBs are necessary.*

- a. Increased awareness and understanding of these disorders among health and education professionals and the public is a necessary step to promote optimal health and well-being among those affected by TS, other tic disorders, and co-occurring conditions. This may lead to earlier identification, appropriate intervention, and reduction in stigma.
- b. Development and dissemination of evidence-based practice to health professionals is necessary to improve the quality of care. This could inform the development of practice guidelines.
- c. Improved access to quality care is needed to ensure that individuals with TS and other tic disorders receive accurate diagnosis and the appropriate treatment for their conditions.
- d. Early identification and treatment of tics may lead to better health outcomes through a reduction of the short- and long-term impact of tic disorders and co-occurring conditions on individuals, their families, and society.
 - i. Additional research is needed to determine whether tics may serve as early indicators of tic disorders and co-occurring MEB conditions, and to assess the utility of integrating the presence of tics into developmental monitoring protocols.

Establish and Strengthen Partnerships to Address the Public Health Gaps Identified for TS

Strong partnerships will result in more effective efforts to ensure that individuals with TS and other tic disorders reach their potential to live healthy and productive lives. Coordinated, multidisciplinary efforts are needed to reduce the negative impact of tic disorders on the health, education, and social functioning of affected individuals, as well as to reduce the economic burden to individuals, their families, their communities and society. Partners in a public health program for TS and other tic disorders include federal agencies, schools, medical and university research centers, the Tourette Syndrome Association (TSA), and professional organizations such as the American Academy of Pediatrics, the American Academy of Child and Adolescent

Psychiatry, and the Child Neurology Society. Partnerships will promote public health activities such as the development or endorsement of evidence-based practice guidelines.

CDC is currently (June, 2011) working with TS partners to address some of the gaps identified. These activities align with the 10 essential services framework focusing on assessment, policy and assurance. Representatives from CDC and NIH are collaborating to identify complementary agency priorities. From these conversations, one area identified as a public health activity was the identification of risk and protective factors for tic disorders and their co-occurring conditions. The [CDC-TSA partnership](#) is disseminating evidence-based materials and education programs aimed at health professionals, school personnel and the public.

CDC is collaborating with the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) to integrate surveillance of TS and other neurobehavioral conditions into ongoing national surveillance efforts, such as the National Survey of Children's Health. This is a critical step in defining the impact of TS, including the prevalence, health care needs, social burden and role of co-occurring MEBs. This partnership has resulted in the first prevalence estimate of children diagnosed with TS based on a nationally representative sample (10).

In addition to surveillance, CDC is collaborating with researchers at the University of Oklahoma Health Sciences Center to determine 1) the prevalence of tic disorders and co-occurring MEB conditions in a community with a diverse population; 2) the rates of health risk behaviors among youth with tic disorders and ADHD, and 3) the feasibility of having teachers help in screening for tic disorders. This study is an extension of the Project to Learn about ADHD in Youth ([PLAY](#)). CDC is also working with the University of Rochester and the University of South Florida to define the impact of tic disorders in youth across multiple domains, including the social and economic burden on the children themselves, their families, and their communities. Data from these studies will help inform the development of measures to identify and monitor TS over time.

Ultimately, the conclusions from the literature review and expert panel will help to frame a public health agenda for TS. In order to have the broadest impact on child health and well-being, this agenda should be developed in collaboration with partners and integrated with similar efforts in other complex chronic conditions.

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<http://www.cdc.gov/NCBDDD/tourette/documents/BridgingTheGapTSandPH.pdf>

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Appendix A: Expert Panel

CDC sought out experts to discuss public health issues and to identify research gaps not captured by a literature review on public health issues related to TS. The experts included neurologists, psychologists, epidemiologists, a psychiatrist, a nurse practitioner in child psychiatry, a parent of a child with TS, and representatives from the TSA. CDC researchers convened a meeting with these experts in September 2009. Prior to the meeting, the experts were asked to identify significant public health issues and gaps in knowledge about the impact or burden of TS, the epidemiology of TS and interventions for TS. These areas, based on the literature review mentioned above and a similar meeting held to discuss attention-deficit/hyperactivity disorder (ADHD), were used to frame the discussion. In addition, each expert was asked to present on significant issues related to the impact/burden, epidemiology, or treatment/intervention of TS at the meeting. Because of the high prevalence of co-occurring MEB conditions among people with TS, and the prevalence of these conditions in the population, experts were asked to incorporate relevant topics of importance to these other conditions. The discussion on each topic involved all meeting participants.

The experts who participated in the meeting are listed below:

Ann Abramowitz, PhD, Emory University, Atlanta, GA
Donald Gilbert, MD, Cincinnati Children's Hospital Medical Center, Cincinnati, OH
Sandra Hollis, LMSW, Albuquerque, NM
Jorge Juncos, MD, Emory University, Atlanta, GA
Jonathan Mink, MD, PhD, University of Rochester, Rochester, NY
John Piacentini, PhD, University of California, Los Angeles, Los Angeles, CA
Lawrence Scahill, MSN, PhD, Yale University, New Haven, CT
John Walkup, MD, Weill Cornell Medical College, New York, NY

Representatives of the Tourette Syndrome Association (TSA) attending were:

Judit Ungar, MSW, President
Gary Frank, ACSW, LCSW, Executive Vice President
Kevin McNaught, PhD, Vice President, Medical and Scientific Programs
Eldridge proctor, MPA, Vice President, Public Policy

CDC staff members present were:

Gloria Krahn, PhD, MPH, Director, Division of Human Development and Disability
Ruth Perou, PhD, Acting CDC Mental Health Coordinator

NCBDDD/DHDD, Child Development Studies Team:

Rebecca Bitsko, PhD
Melissa Danielson, MSPH
Lisa Matthews, MS, EdS
Dianne Ochoa, CPM
Lara Robinson, PhD, MPH
Camille Smith, MS
Jeannette Bloomfield, MS
Susanna Visser, MS

Rebecca T. Leeb, PhD, a current member of the Child Development Studies Team, was not present at the 2009 meeting but made significant contributions to the report.