



Selective Mutism

For more information: www.selectivemutism.org

What is Selective Mutism (SM)?

Selective mutism (SM), formerly called elective mutism, is defined as a disorder of childhood characterized by an inability to speak in certain settings (e.g. at school, in public places) despite speaking in other settings (e.g. at home with family). SM is associated with anxiety and may be an extreme form of social phobia according to researchers and clinicians who are familiar with the disorder (Black & Uhde, 1995; Dow et al., 1995, Dummit et al., 1997, Kristensen, 2001; Leonard & Dow, 1995).

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders, referred to by clinicians as the DSM-IV, (APA,1994) recognized that the social anxiety and avoidance characteristic of social phobia may be associated with SM, and thus, both diagnoses may be given. More than 90% of children with SM also meet the diagnostic criteria for social anxiety disorder, now termed social phobia (Black et al., 1996).

Diagnosis of other comorbid anxiety disorders are also commonly diagnosed with SM and social phobia (Biedel & Turner, 1998). The name change from "elective" to "selective mutism" in DSM-IV deemphasized the oppositional behavior connotation that a child elected not to speak and rather emphasized the characteristic of the disorder, that there are select environments in which speaking does not occur (APA, 1994). The term selective mutism is consistent with new etiological theories that focus on anxiety issues (Dow et al., 1995).

The current edition, DSM-IV-TR (APA, 2000) states that the following criteria must be met in order to qualify for a diagnosis of selective mutism:

An inability to speak in at least one specific social situation where speaking is expected (e.g., at school) despite speaking in other situations (e.g., at home); The disturbance has interfered with educational or occupational achievement or with social communication; The duration of the selective mutism is at least one month and is not limited to the first month of school; The inability to speak is not due to a lack of knowledge of or discomfort with the primary language required in the social situation; and, The disturbance cannot better be accounted for by a communication disorder (e.g. stuttering) and does not occur exclusively during the course of a pervasive developmental disorder, schizophrenia or other psychotic disorder.

Consistent with current research, SMG believes that Selective Mutism is best understood as a childhood social communication anxiety disorder. SM is much more than shyness and most likely on the spectrum of social phobia and related anxiety disorders.

Are there other associated behaviors or personality traits?

Associated features of SM may include profound shyness, little eye contact, social isolation, fear of social embarrassment, withdrawal, clinging behavior, compulsive traits, negativism and oppositional behavior when attempting to avoid feared social situations, and temper tantrums, particularly at home. Since children are unable to communicate verbally, they may opt for using nonlinguistic cues such as gestures, nodding or shaking the head to get their messages across. A child may pull or push objects and obstacles, and in some cases, communicate in monosyllabic, short or monotone utterances or in an altered voice (APA, 2000). Some of these behaviors may not be present at the onset of SM. At the onset of SM, children may often stand motionless and expressionless due to anxiety and then slowly progress from nonverbal and non-communicative stages to communicative and verbal stages in treatment (Shipon-Blum, 2001). Fundis et al. (1979) reported that 71

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percent of the children in their studies displayed difficulty in performing motor activities and had bowel and bladder problems or, enuresis and encopresis. Some individual with social anxiety symptoms may also experience parureis, the fear of using public restrooms perhaps to fear of making sounds while urinating that others may hear (Stein & Walker, 2002).

How common is this problem, to be worthy of our attention?

DSM-IV-TR estimates that SM affects 1 in 1000 children referred for mental health treatment (APA, 2000). However, several researchers have suggested that the true prevalence of SM in the general population is largely underestimated (Bergman et al., 2002; Hayden, 1980; Hesselman, 1983; Kupietz & Schwartz, 1982; & Thompson, 1988). Recent studies show that SM is not as rare as it was previously believed to be but is comparable to other, widely known disorders of childhood. A study targeting a large sample of children in a Los Angeles, CA school district identified children who met the diagnostic criteria for SM and found a prevalence rate of 7.1 per 1,000 children (Bergman et al., 2002). A subsequent study in Israel found an almost identical prevalence rate (Elizur & Perednik, 2003). These numbers suggest that SM has a higher prevalence than autism (.5 per 1000), major depressive disorder (.4 to 3 per 1000), Tourette's disorder (.5 per 1000), obsessive-compulsive disorder (.5 to 1 in 1000) and other well-known disorders. In comparison to other studies, which only accounted for diagnosed cases of SM, provides evidence that a large number of individuals with SM are undiagnosed or misdiagnosed. Parents of children with SM who enter treatment often report that their child was misdiagnosed with autism or another pervasive developmental disorder, mental retardation or oppositional-defiant disorder. Most are told (if anything) by uniformed professionals that there is nothing wrong with their child, that their child is "just shy," or will grow out of this behavior. Thus, the lack of awareness among educators and treating professionals leads to delays in diagnosis and missed opportunities for treatment.

SM is slightly more common in females than in males. Although the duration of SM often lasts for several months, left untreated, it may sometimes persist longer and may continue for several years (APA, 2000). The average age of onset is 5 years, even though most parents report that their children's symptoms began years earlier (Leonard & Dow, 1995). In his treatment of children with SM, Thompson (2000) found that children who establish speech in previously mute settings before age eight typically become verbal in school and social settings within one year. Children who demonstrated longer-term mutism were likely to continue their silence into upper grades and into adulthood (Thompson, 2000). While reports of older children and adolescents with SM are scarce, based on our collective clinical experience, individuals who to enter into treatment later may suffer from depression and other disorders in addition to SM but can make treatment gains and overcome SM without it continuing into adulthood.

How does SM differ from shyness?

Shyness is a normal personality trait. It is marked by a voluntary tendency to withdraw from people, particularly unfamiliar people. Everyone has some degree of shyness; it may be experienced a lot, a little bit or somewhere in between. Shyness, like other inheritable traits, such as height and eye color, is largely influenced by genes (Stein & Walker, 2002). Shyness is not a psychiatric disorder like SM, social phobia and avoidant personality disorder which all characterize different forms of extreme inhibition that interferes with a person's daily functioning. People who are shy are able to function adequately in society. Shyness may fluctuate and change as a person matures and encounters new social challenges without treatment (Carducci, 1999). People with psychiatric disorders such as SM do not adapt well to social situations nor are they able to communicate effectively with others. They may have limited academic and occupational achievement and require treatment in order to overcome their symptoms and function at an adaptable level.

How is a child evaluated for SM?

A trained professional familiar with SM and/or childhood anxiety disorders will generally begin by conducting a thorough assessment to accurately diagnose the condition, rule-out similar or comorbid conditions, and formulate a treatment plan. Information will be gathered about the child's developmental history (including achievement of developmental milestones and whether or not there were any delays in hearing, speech and motor and cognitive development), family history (including determining whether or not other anxiety

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disorders are present in the family), behavioral characteristics, medical history, and significant stressors (including divorce, frequent moves or a death in the family). The treatment professional may also request permission to contact the child's school, physician and other significant players in the child's life to gain further information about the child's behavior in other settings. It can also be helpful for the professional to view a videotape of the child in a comfortable setting and/or do an observation of the child before the child has met the professional so that the child's behavior will not be influenced by the professional's presence.

The professional will then arrange to meet with the child. While most children with SM will not speak to the treating professional, some may be comfortable in the treatment setting and speak normally, although this behavior does not rule out selective mutism. The "selective" nature of the mutism varies from child to child and setting to setting so this needs to be considered in conducting a thorough assessment. It is important that the professional develops rapport with the child and evaluates his/her behaviors, preferably in more than one setting. An appropriate professional will be able to interact with the child whether or not he or she is speaking and use appropriate methods to begin to develop a therapeutic relationship.

Because some children with SM may have difficulties with expressive language or other communication disorders, a speech and language evaluation might also be necessary. In addition, a physical exam (including testing of hearing), standardized testing, psychological assessment and developmental screenings are often recommended, especially if the diagnosis is not clear.

What is the prognosis for SM? Will my child overcome this?

The prognosis for children and adolescents who are treated for SM appears to be excellent. With appropriate treatment, SM is often overcome successfully. Without treatment, however, SM is more likely to persist and comorbid symptoms in addition to SM are common. Longitudinal studies showing the course of SM following treatment are needed, however, in clinical settings, most children with SM show significant improvement.

What is the Selective Mutism Group (SMG)?

SMG, part of the Childhood Anxiety Network, is a nonprofit organization dedicated to providing information, resources and support to those impacted by a child with the anxiety disorder known as Selective Mutism (SM).

Selective Mutism does not have to be the intractable disorder once written about in outdated medical literature. In fact, with early diagnosis and the right treatment, the prognosis is excellent. Whether you are a parent of a child with SM, a teacher, a treating professional, or other individual interested in learning more about this often misunderstood childhood disorder, you've come to the right place.

SMG is the nation's premier resource for information on SM. We provide a network of professionals, families and affected individuals across the world who understand the struggle of living in silence. You are not alone. You deserve accurate information and meaningful support. SMG is here to help. We hope you will enjoy our website, share its contents with others, and help us in our mission to *Rid the Silence!*

SMG's Mission and Values

Our Mission

The mission of the Selective Mutism Group and the Childhood Anxiety Network is to increase public awareness of selective mutism and related childhood anxiety disorders, to promote greater understanding of these disorders through education, support of research and to provide support to professionals, affected individuals and their families.

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We are parents, grandparents, siblings and family members from all walks of life: accountants, artists, engineers, carpenters, electricians, librarians, lawyers, veterinarians, stay-at-home-moms, musicians, secretaries, dentists, nannies and bookkeepers.

We are also physicians, psychologists, psychiatrists, therapists, social workers, speech and language pathologists, teachers, school administrators, occupational therapists, counselors, nurses, researchers, students and other health and education professionals.

What we all have in common is that we have witnessed the pain of children who suffer in silence and we have experienced the frustration of not knowing how to help them. We have come together to form an online community to help one another and, most importantly, our children.

We share experiences and knowledge, fulfilling our mission to promote public awareness, to educate and support the expansion of research about selective mutism, and to speak out for our children who are unable to speak for themselves. We pride ourselves on being the premier information source for SM.

Our Values Support What We Do

SMG exists because of a belief in the social responsibility to bring about progress for all individuals who suffer from selective mutism. We believe that there is an obligation to foster awareness and understanding so that children, adolescents and adults affected by selective mutism will have access to the help they need to overcome their anxiety and reach their full potential of personal growth and participation in society. We also believe that lack of financial resources and language barriers should not stand in the way of obtaining this treatment and support.

Driven by compassion that is born out of our personal and professional experiences with SM, we share a commitment to providing the tools and resources needed to support individuals and families, and to educate schools, professionals and other members of our community. We are consistently responsive to the needs of our constituents.

By drawing on knowledge by leading experts in the field of childhood anxiety, we create high quality educational materials and conferences and earn the credibility and respect of school and health professionals. To ensure the reliability of information that is disseminated through our website, print materials, conferences and all other communications, we consult with professional advisors and other experts, reference peer-reviewed articles, and follow accepted treatment and research protocols. Our reputation for being the leading information source on selective mutism allows professionals to learn the current best treatment practice guidelines and empowers families to advocate for effective treatment strategies and school accommodations for their children.

Our reputation is upheld by showing integrity and honesty in all of our actions. We are fully accountable for educational resources we create and compile (unless otherwise noted) and are good stewards of financial resources that are entrusted to us. We uphold the highest standards of fiscal responsibility and ethics.

To achieve true change and acceptance for our children, we are proactive in promoting research, bringing together experts, and actively disseminating the most current information about selective mutism. We seek out every possible opportunity to educate others about evidence-based treatment strategies so that all children will have access to effective treatment methods. We advocate for early diagnosis and screening of population groups of children that might be vulnerable to developing selective mutism and encourage parents and professionals to advocate for appropriate school accommodations and other resources that may be needed to help our children.

How SMG Started

The history of the organization, now known as the Selective Mutism Group, dates back to the mid-1990's. At that time, an interested parent of a child with selective mutism, Mr. Robert Helta, developed a website designed to

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provide information on selective mutism. Like other parents, Mr. Helta was frustrated by the lack of resources available on this childhood condition. During this period, the organization as it stands today was founded by the collaboration between Mr. Helta, and the now well-known physician, Dr. Elisa Shipon-Blum.

Dr. Shipon-Blum was also the parent of a child with selective mutism. Driven by her personal experience, Dr. Shipon-Blum volunteered her time and medical expertise to assist Mr. Helta with developing the website content. By the year 2000, the Selective Mutism Group had already begun to attract other professionals and parents. Dr. Shipon-Blum collaborated with these professionals and parents and hoped to increase public awareness of this often misunderstood childhood disorder. She provided support to website viewers via email, reviewed scientific articles about selective mutism and related anxiety disorders to develop website content, supported a web-based study on selective mutism with Dr. Lindsey Bergman and staff at the University of California at Los Angeles (UCLA) and formed the first professional advisory committee comprised of leading professionals in the field of childhood anxiety. The Selective Mutism Group obtained 501(c) 3, nonprofit status in the year 2001 as The Childhood Anxiety Network. From 2001 to 2007, the organization was known as the Selective Mutism Group~Childhood Anxiety Network (SMG~CAN) to help promote awareness of selective mutism as an anxiety disorder.

Since the founding of SMG~CAN, several key events occurred that made SMG~CAN the primary go-to resource for selective mutism. Volunteers worked tirelessly to promote awareness of selective mutism (SM) as an anxiety disorder by providing exhibits at major medical and psychological conferences in the country. In 2002, SMG~CAN began to host an annual retreat and conference devoted solely to education about SM and support to families affected by it. SMG~CAN was recognized in the media, and Dr. Shipon-Blum soon became a leading expert on SM. She participated in interviews for major newspaper and magazine articles and took part in a television documentary, *Afraid of People*, along with parent, Sherry Heckman and her daughter who had selective mutism.

As SMG~CAN continued to grow, the organization joined together the few researchers, treating professionals, and educators with knowledge about selective mutism. Beginning in 2002, SMG~CAN participated in the first research study on the genetics of selective mutism in collaboration with lead researcher, Dr. Denise Chavira, and colleagues at the University of California, San Diego (UCSD). In this same year, the SMG~CAN website was used for recruitment of participants for a social anxiety research study by Dr. Deborah Biedel of the University of Maryland. Volunteer Adrienne Wallage led the formation of the SM International Connections groups to provide information on selective mutism in other countries, including her homeland of Israel. SMG~CAN's Board of Directors began to expand and the organization hired its first Executive Director, Dr. Christine Stanley, a veterinarian by profession, and the parent of a child with SM who managed the organization's daily operations for three years. Expert online chats were born in 2003 for SMG~CAN members to learn from and ask questions of experts in the field. Informational handouts about SM began to be distributed nationally to professionals and educators by volunteers in many of the 50 states with the formation of the SM Connections program led by Laurie Gorski and Lori Dabney, both parents of children with selective mutism. By 2004, key sections of the SMG~CAN website were translated into Spanish in order to reach an extensive audience of Hispanic families and professionals. In 2005, SMG~CAN developed relations with another SM advocacy group in the United Kingdom, Selective Mutism Information and Research Association (SMIRA). SMG~CAN also supported several student research projects, theses, dissertations, and reduced fees to encourage student conference attendance to increase knowledge amongst our future educators and treating professionals.

Between 2005 and 2007, SMG~CAN began to restructure the organization in order to support the needs of its growing number of members, website visitors, and professionals that contacted the organization. The Board of Directors expanded to include both treating professionals and business professionals. SMG~CAN presented six annual conferences by 2007 and co-sponsored several conferences in collaboration with the Selective Mutism Anxiety and Research Center (SMART Center), the private practice of Dr. Elisa Shipon-Blum founded in 2003 to serve the needs of the many individuals seeking treatment. In addition, SMG~CAN was represented at several other conferences and professional training seminars including the Anxiety Disorders Association of America conferences.

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2007 has been a period of rapid growth for SMG-CAN. The organization endured a great amount of internal change and restructuring. The Board of Directors expanded to include expertise in several key areas and adopted a new committee structure led by Board members and dedicated volunteers. Both regular and professional memberships have increased and purchasing of the organization's books and products related to selective mutism has been substantial. The organization also launched its first Annual Campaign and national Bowl-A-Thon to solicit donations from generous contributors who are dedicated to help SMG~CAN succeed in its mission and continued expansion. SMG~CAN is especially grateful to have the support needed to update its website, the central entity of the organization and leading resource on SM, to better respond to the needs of those affected by SM. On average, our website receives over 1,000,000 hits per month and thousands of individuals learn about SM through the resources provided within it.

We are proud to say that by addressing our mission, more and more individuals are becoming aware of selective mutism as an anxiety disorder.

The Selective Mutism Group (SMG) has always advocated primarily for the recognition of SM as it relates to other anxiety disorders. SMG has been the primary operating entity of the Childhood Anxiety Network (CAN) since its founding. As selective mutism continues to increase in recognition amongst both professionals and the general public, the organization has decided to brand itself as SMG, with a crisp, new logo that captures the essence of our history and the vision of our future.

The meaning of the ribbon in our logo is representative of the gift our efforts bring to our children: a transition from a low point of discouragement to a high point of victory. Some have also commented that the ribbon symbolizes the transition from a frown to a smile, showing that we are instilling happiness in our children as they become more understood, and as their anxiety is overcome. The term "selective mutism" and SM can now stand alone, as we are closer to making this disorder a common household name like ADHD, autism, and other well-recognized disorders of childhood.

While still embedded in the family of the Childhood Anxiety Network, SMG is stronger and more prominent as an entity in itself that facilitates awareness and recognition of SM as an anxiety disorder all on its own.

Taken from www.selectivemutism.org