

### Selective Mutism Group~Childhood Anxiety Network Speaking Out for Our Children

#### **Top Ten Myths About Selective Mutism**

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Although it was first described 125 years ago (and labeled aphasis voluntaria at that time by a German doctor, Kussmaul), relatively little has been studied or written about the childhood anxiety disorder now known as selective mutism. In reading through the sparse body of literature in textbooks and journals, it is not difficult to see why so many selectively mute children are being misdiagnosed and receiving inadequate or inappropriate therapy. Unfortunately, many inaccurate theories about the cause and basis of selective mutism have gained acceptance among medical and educational professionals in spite of the lack of supportive evidence. In the vacuum of inadequate research, it seems that these myths have arisen to fill the void of true knowledge and understanding.

Because many of the older theories about selective mutism are currently contributing to the confusion and inappropriate treatment of children with this disorder, this article is an attempt to debunk the following myths.

#### Myth #1: Selective mutism is extremely rare.

The most recent study showed a prevalence rate for Selective Mutism of 7.1 per 1,000 children (Bergman, 2002). Older surveys ranged from 0.08 %, or 0.8 per 1,000 (Fundudis, 1979), to 1.8 per 1,000 children (Browne, 1979). Variation may be due to the methods of surveying used, the age of the children in the sample population, or inadequate recognition of symptoms by parents, medical, and educational professionals. Lack of knowledge about selective mutism leads to many of these children being labeled as "just shy" or misdiagnosed as autistic, so that any reports of the number of cases are likely to be falsely low.

Even the lower estimates show that SM is more common than other childhood disorders

such as autism, cystic fibrosis, spina bifada, and muscular dystrophy. Presumably because

of greater public awareness, though, these have received much more funding for

research and thus are better understood.

### Myth #2: Selectively mute children are typically severely emotionally disturbed, usually because they have suffered abuse, neglect or trauma.

This assumption is often seen in older case reports, although no evidence is offered; instead, there is an apparent presumption that children would not exhibit excessive fearfulness in social interactions unless their life experiences had taught them to react in that way. Recent advances in understanding the neurobiological circuitry of anxiety have given reason to believe that human beings are hard-wired to be vigilant to danger, and that in some individuals the gating mechanisms for this circuitry are overly sensitive. Thus, for these individuals, normal life events do trigger anxious responses in certain contexts.

The fear of being placed under suspicion of abuse may prevent parents from seeking help for their children. While there may be a legitimate concern that selectively mute children would be unable to speak out if they were victims of abuse, there is no reason to assume that such abuse is any more likely to be occurring with these children than with the average child (Black, Uhde, 1996).

#### Myth #3: Families of children with selective mutism are typically dysfunctional.

While epidemiological studies have shown a high incidence of social anxiety and other forms of anxiety and/or depression in the close relatives of selectively mute individuals, there is no evidence that family pathology causes the symptoms of selective mutism. Discussions in older literature characterize parents, particularly mothers, as being either poorly attached or overly attached to selectively mute children. This notion is very similar to the now-discarded theory about autism that was prevalent several decades ago, when poor maternal bonding was thought to be the cause of that disorder. In both cases, it is likely that any observed bonding difficulties between parent and child might be a result of the disorder rather than the cause.

## Myth #4: Selectively mute children use their silence as a form of passive aggression, manipulation, or defiance.

Oppositional behavior may be in the eye of the beholder (or perhaps we should say, in the ear of the frustrated would-be listener), but taking this view of mutism implies a conscious choice of silence by the selectively mute child. If selective mutism does represent a speech phobia, it is not surprising that these children appear to stubbornly resist attempts to make them speak, just as, for example, a person with a fear of flying would not willingly board an airplane.

Additionally, it is wise to remember that power struggles between adults and children are no-win situations and the only winning strategy is to avoid them. One might ask who is being more oppositional, the child who is afraid to speak or the adult who stubbornly insists that the child must speak.

#### Myth #5: Selective mutism is extremely difficult to treat.

Historically this may have been true, but when treatment is approached with an understanding of selective mutism as an anxiety disorder, most children make excellent progress. Anecdotal evidence does suggest, however, that early diagnosis and multimodal treatment is critical for the greatest chance of successful treatment outcome.

### Myth #6: Selective mutism is really just severe shyness; most children will grow out of it.

Shyness is a non-pathologic personality trait but it is not paralyzing, as is selective mutism. The inability to speak when speech is expected leads to severe incapacitation, inability to perform well in school without special accommodations, and poor self-esteem because of the frustration and anger reflected by teachers, peers, and others.

Although a percentage of selectively mute children apparently do overcome mutism without formal intervention, anecdotal reports indicate that these individuals continue to suffer from other manifestations of anxiety. And, since there is no way to identify which children may "outgrow" it, physicians and educators should recommend evaluation of any child meeting the DSM-IV criteria for selective mutism for one month or more. Otherwise, the window of opportunity for optimal treatment results will be missed in many cases.

One of the greatest frustrations for parents of selectively mute children is that if they seek advice of a pediatrician for a young child not speaking outside the home, they are usually told that their child is just shy, and then at the onset of kindergarten they are informed by school officials that the child is severely disturbed and needs psychological help.

## Myth #7: Adults who work with selectively mute children should let the children know that there is a firm expectation for speech.

The expectation of speech is a trigger of severe, paralyzing anxiety for selectively mute children. Instead of the embracing the simplistic notion that mutism will stop when reinforcers are removed, teachers, parents and therapists must understand that these children need interventions to reduce anxiety, as well as instruction on recognizing and coping with their anxious feelings before any speaking goals are placed on them. Allowing children to communicate non-verbally does not prolong mutism but actually serves to increase the child's comfort level (as well as allowing the child to have his or her basic needs met during the period before they are able to speak). It should be noted that many mute children do not need external motivation to speak; they simply need supportive, encouraging attitudes so they can discover that they can begin speaking in situations where they previously felt paralyzed by anxiety.

Myth #8: Selective mutism is a form of autism or is on the autism spectrum. Although the DSM-IV (the manual used by mental health professionals to diagnose)

specifically rules out an autism diagnosis, there is apparently still a great deal of confusion

over this point. The most obvious distinguishing feature of selective mutism is the selectivity; although autistic children may exhibit symptoms of mutism, the behavior is not variable with situation, environment, or audience. One of the best ways for clinicians to rule out autism is to observe videotape of the child in his or her comfortable environment (usually in the home). Most parents know that selectively mute children are very talkative and boisterous when they are at home, and if doctors and teachers can observe that behavior it becomes clear that the child is not autistic.

Another complicating factor is that the DSM-IV criteria for selective mutism do not list some of the associated behaviors, such as blank expression, lack of eye contact and other body postures that are often seen when selectively mute children are anxious. It is possible that clinicians unfamiliar with this disorder, on reading the DSM-IV, would not recognize that these behaviors are also part of what many believe to be the syndrome of selective mutism. Research is needed to more clearly define all of the characteristics that tend to define Selective Mutism, so that future revisions of the DSM can explain these features and assist correct diagnosis.

Myth #9: Selectively mute children tend to be below average in intelligence. This misperception is probably due to the difficulty educators have in evaluating the abilities of SM children by traditional verbal methods. Alternative testing methods and use of accommodations such as tape recording usually allow a more accurate assessment for these children. It remains to be proven, but most clinicians that work with large populations of selectively mute children believe that they tend to be above average in intelligence, and that many of them are gifted. Again, more research is needed.

# Myth #10: Children with selective mutism usually don't function well in the mainstream classroom and often shouldn't be promoted to the next grade level because they aren't speaking.

Unless other factors are involved, most selectively mute children do very well in the regular classroom setting, provided there is not pressure to speak. The accommodations that are needed are minimal and should be possible in most any school. When verbalization is required, selectively mute children should be permitted to use alternative methods of completing assignments, such as tape recording at home or performing oral assignments one-on-one or within a small group setting when possible. Federal law mandates that children with disabilities have accommodations to place them on a level playing field with non-disabled individuals; therefore, the inability to speak in the school should not affect a child's grades or cause retention.

In summary, the lack of knowledge about selective mutism is a serious barrier to helping these children, but the incorrect ideas discussed here are even more damaging. Selectively mute children have the best chance of overcoming their disability when there is an alliance between parents, teachers and therapists; currently, though, parents must risk false accusations of abuse, possibility of misdiagnosis, and inaccurate and misleading advice on

how to help their children. One of the great tragedies for these families is that not only are the children trapped in silence, but the parents' voices are also stifled. Despite the fact that schools and therapists often do not know how to treat selectively mute children successfully, there is often too little attention paid to parental knowledge and instinct about their children.

Teachers also tend to be caught in the middle, with inadequate training about this disorder and the advice of well meaning but misinformed school administrators and psychologists to maintain firm expectations for the children to speak.

Fortunately there has been a shift in more recent publications, and several current authors do stress that selective mutism most likely has a biological basis rooted in anxiety. While there is agreement that more research is needed to substantiate the neurobiological and possibly genetic factors, there are already a number of reasons to favor this newer conceptualization over the older theories. Most notably, selectively mute children treated from the anxiety perspective (using protocols based on behavioral therapy and/or pharmacological treatments for anxiety) appear to be more likely to recover or make significant progress in overcoming selective mutism, when compared with case reports in the older literature of children whose therapy was more dynamic and psychoanalytic in nature. As more people are educated about the recent and ongoing research about selective mutism, there is hope that the myths will yield to scientific knowledge and these children will be freed from their walls of silence.

To learn more about selective mutism and how you can help to Rid the Silence, please visit www.selectivemutism.org
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