



Increasing Public Awareness about Disabilities and Their Impact on Families

October, 2003

Parents who feel stressed and hassled from going out in the community with their child with a disability say they wish people knew what their life is like. Life is different in a home when a child in the family has a disability. Mealtime, bedtime, relaxation time, the demands of the disability may impact every part of the day in big and small ways. The impact of the disability on the family dynamics is also not limited to what happens inside the house. It also extends into the community when the family engages in normal community activities: shopping, working, playing, worshipping, etc.

Many parents are noting a challenge in the way the public perceives them. Strangers sometimes ask intrusive questions or volunteer opinions about a child's appearance or behavior. Even people who have the best of intentions may come across as being rudely curious, intrusive or unkind. While the child's disability places extra demands on parents, so does interacting with the public.

It can be tempting to come up with a stinging comment, have the last word and keep others at a distance, but there is more to be gained by thinking about how to bridge the gap to build supportive connections with community members. Today people with disabilities stay and live as community members. This represents a change from an older approach that separated people who were different. Ideas people have may reflect an old way of thinking that seems remarkably uninformed and misinformed.

Additionally, as hidden disabilities, such as autism spectrum disorders and other behavioral disabilities become more prevalent, it is painful to experience the censure that assumes the behaviors are the result of bad parenting, or lack of discipline. Sometimes parents choose to use the circumstances of their child's life as a means to educate others. Other parents want tips about how to provide information to those they meet and still be able to complete their without interruption.

Ideas or Strategies for Public Awareness

- **Local newspapers** seek human interest stories as a way to engage their readers. Talk to the editor or a reporter and suggest that parents either write their own stories or be interviewed for an article. Present your proposal with a positive perspective – wanting to inform the public, not as a forum to complain. Parents who represent various disabilities could share their stories over a period of weeks or months (like a story about a different disability once as month) as a way to describe the disability and how the disability impacts the family.
- **Community Service Groups** meet frequently and are looking for speakers. Talk to local service organizations like the Rotary, Lions Club, Sertoma, Elks, Legions, church groups, etc. Put some time and effort into making an interesting presentation; get specific enough to keep the attention of the audience. This could be an effective approach for one parent or two. Use Flamestarter #28, Sharing Your Parent Story, as a guide. Make a point to be prepared, use time well and respect the time limit.

(continued)





Increasing Public Awareness about Disabilities and their Impact on Families

(continued)

- **Develop a slide show** sharing the stories of a few families. Parents select favorite photos of their child and family and write their story, carefully constructing the point(s) they want to make, and the information they would like the public to know. They narrate their story while their photos appear onscreen. Soft background music can enhance the presentation if chosen carefully. The show just needs a welcome and personal introduction and it can do the talking. This approach can be less stressful than a live presentation for a nervous presenter. Bring the show to the groups listed above, to the schools, etc.
- **Make a “documentary video”** about the concepts of the impact of disability of a family’s life. As a team, outline the main points for public awareness. Some main point topics might include:
 - The amount of paperwork
 - The loss of freedom to be out in the community because of the severity of the child’s ability to cope and self regulate
 - The invasion of the system into the family’s life, the “fish bowl experience”
 - The daily need for technical, medical procedures, skills that parents normally don’t need?
- **Message buttons.** One mother reported successfully informing others by having a button made that said, “I love my child with autism.” She wore it when taking her child out in public.
- **Information flyers.** Make a brochure or information sheet about the disability and how it manifests itself. Make several copies and keep them handy – in the back of the wheelchair, or in a purse. These can be wordlessly shared in public or at team meetings with others as needed. Talking is optional.
- **Develop a targeted list** of places to take the message. Considers newspapers, city publications, radio, public access TV, ITV, church newsletters, schools, day care providers, appropriate college courses like nursing, child care, teachers, doctors, social workers, etc.
- **Make a general list of Do’s and Don’ts** to share with the public that tells specifically what you want from them. A sample list follows that can be used as a starting point.

(continued)





Increasing Public Awareness about Disabilities and their Impact on Families

(continued)

You Can Help Me By....

- Choose to believe that I am doing my best as a parent. There is always more to learn, but I am trying to be a good parent as best I know how.
- Remember that some hidden disabilities are not physically obvious.
- Be alert to my silent social cues. Does it appear that I would welcome your approach and questions? Offer a hand if it looks as though it would be helpful – like opening the door, carrying grocery bags, getting the wheelchair out of the car, etc. Don't come up to me if I am glaring at you, avoiding eye contact, or when my child is experiencing a meltdown.
- Use people first language as a way to respect the dignity of my child's life.
 - Say "the child with autism" ————— not "an autistic child".
 - Say "uses a wheelchair" ————— not "crippled or wheelchair bound".
- When children are curious about people with disabilities,
 - Respond openly, don't whisper.
 - Use factual, neutral terms to answer questions. For example, say:
 - "He uses a wheelchair to get around."
 - "She is really upset."
 - "He is having a bad day."
 - "She had some surgery, etc".
 - Don't avoid or patronize.
- Support me by informing yourself. Make a point to learn and seek out information, removing some of the weight of educating others from my shoulders.

