



Social Skills Development in Children with Hydrocephalus

As the first generation of children shunted for hydrocephalus mature into adulthood, it has become apparent that some of them will have difficulty developing their social skills. We know that the majority of children diagnosed with hydrocephalus will live into adulthood, and be smart enough to make it in this world. But will these children be happy?

For most of us, happiness means friends, the move from isolation to inclusion. It means comfort with social interaction so that other people are motivated to actively seek out our children, or at the very least, not ignore them. The acquisition of social skills is critical for social inclusion. If some areas are weak, we need to understand that these skills can often be broken down into component parts and taught like other skills such as addition or teeth brushing.

A recent study done by the National Institute of Health found that the greatest concerns of parents of special needs children regarding their social skills were:

- Talking over differences without getting angry
- Persistence when facing frustration
- Refusing requests politely
- Taking turns while talking
- Understanding rules
- Following directions
- Waiting when necessary

Of course, these problems are not limited to children with special needs. However, for most of us, learning the social skills necessary to handle these situations is automatic, while for children with learning disabilities and special needs, often it is not.

Most of our social learning is done automatically, by seeing, copying and conditioning. That is, social skills are learned incidentally, without formal instruction. However many children with hydrocephalus have learning problems that make it difficult, or nearly impossible, to pick up the verbal and non-verbal cues necessary for the acquisition of social skills.

Difficulty in perceiving non-verbal cues can create serious social problems. Children with hydrocephalus often mis-estimate distance and spatial relationships. They get too close to other people (called "getting in your face"), or they stay back too far. Getting too close will cause others to back off and find an excuse to escape. Staying back too far makes eye contact difficult, puts them out of reach of voice range and is likely to cause others to ignore them.

Children may also have difficulty picking up other social cues, such as those from clothing for example. Someone dressed in a suit and carrying a briefcase tells us, "I am an authority". If a child

doesn't pick up such cues, they might not figure out who is the authority, boss, teacher, or even the "boss kid." And, as a child, if you can't spot the leaders you may end up imitating the school nerd with the high probability that you will then be socially scorned or ignored.

Children who have a problem with non-verbal cues also often have difficulty perceiving intonation (the way in which the speaking voice emphasizes words). For example, consider the youngster who hears that a party is being planned and goes up to the 'boss kid' to ask if they can come. The 'boss' responds, "Yeah, sure, I REALLY want YOU at my party." If the youngster shows up at the party, it is sure to be a heartbreaking experience. The child has heard the WORDS ("I want you"), but not the TONE ("I would rather hang by my thumbs than have you at my party"). Errors such as these can be incredibly painful for kids who are not attuned to such nuances as tone, rhythm or pitch.

Other important non-verbal cues are posture and facial expression. If a child can't read faces very well, he/she will likely interpret things incorrectly. Often children with hydrocephalus perceive only two kinds of facial expressions, 'happy' and 'mad', and perhaps 'sad'. This understanding is not enough to get along in the world. They need to perceive such subtleties as 'quizzical', 'reflective', and others, and they are expected to learn them incidentally.

It is known that some youngsters with hydrocephalus will be slower in acquiring such skills as walking, talking and hand-eye coordination. With time, remediation and early intervention however, these skills are often obtained. But what about Social Skills? If a child lags behind, will he/she eventually catch up on these skills on their own, or is intervention important at an early level?

It is believed by many neuropsychologists, especially those that have worked extensively with children with hydrocephalus, that intervention is vital because, even if the child does catch up on their own, it will probably happen over time, and some skills may always be missing. If undeveloped social skills do come later in life, a youngster may be exhausted, reclusive or self-defeating in interactions with others- having had so many rejections and bad experiences that he/she refuses to continue to extend themselves socially.

Parents do not need to wait for this self-defeating behavior to happen if they realize that many of these social skills can be taught. The first step in this process is a neuropsychological evaluation. An in-depth evaluation, conducted by an experienced neuropsychologist, can pinpoint areas of deficiency so that the most effective ways can be identified to teach youngsters the social skills they need. Although schools are now mandated to provide many types of evaluations, often the in-depth testing and remediation plans necessary to pinpoint areas of deficiency are best carried out by experienced specialists. Every child is guaranteed an appropriate education by federal law, but the law does not guarantee that a child will be evaluated in a way that pinpoints his/her strengths and weaknesses precisely so that an optimal remedial program can be formulated, and modified if necessary, to meet available resources.

Your child's neurosurgeon, neurologist or pediatrician may be able to recommend an experienced neuropsychologist. Sometimes the hospital social worker or a clinical nurse specialist has recommendations. And don't forget to ask other parents. Networking can often be the best way to gain information.

The cost of neuropsychological evaluation can run anywhere from \$350 to \$1000. The cost is dependent on the number of tests given, amount of time spent in assessing data and preparation of the final report, which should include plans for remediation and intervention. Some insurance plans will cover the cost. Check your policy. Some policies will pay if the testing is for diagnostic purposes, others will not. It's usually a good idea to have the doctor write a "prescription" stating that a neuropsychological evaluation is necessary because your child with hydrocephalus is "at-risk" for developmental and social delays.

Unfortunately, the move from isolation to inclusion and the acquisition of social skills so necessary for our children's well being, is not often well addressed in the school setting. At present, there are few good programs that teach social skills through the schools. However, once an evaluation has been completed, and recommendations for intervention and remediation compiled, parents should contact their child's teacher or special education coordinator for help in implementing the program. As usual, parental involvement and advocacy will most likely be necessary.

There are no absolutes or guarantees that even with a thorough neuropsychological evaluation known interventions and strategies will work for all children. However, this is just one more way in which parents can help their children with hydrocephalus attain the high quality of life they desire for them, and that they deserve.

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