

# Family Considerations with a Child with an ASD

## Accepting the Disability as a Part of Your Lives

When a child is diagnosed with an autism spectrum disorder (ASD), family members will suddenly need to make changes in their expectations of daily life. This is a hard transition to make because the disability is so complex, and the learning has not yet taken place to be able to predict the kinds of hurdles that may be met. They are, in essence, going into unknown territory without a map to guide them. This is especially true if the child is diagnosed at a very early age, since it is so hard to for medical professionals to predict what the progress of an individual child might be. Sometimes the doctor may give extensive information, but the family is not yet ready to process it. Sometimes doctors don't have a good understanding themselves of the impact of the disability upon the family, or even of the condition itself if they have little experience with autism spectrum disorders. Whatever the reason, families are often left to deal with the trauma of a disability without an idea of what the prognosis will be. The NOT knowing is often much harder than the KNOWING. This is a very difficult time when love and understanding from extended family members and friends becomes essential because the level of acute stress can be very draining on a family's resources of time, energy, and emotional strength.

Parents often feel the pressure to learn everything, and obtain all the necessary resources and supports immediately, and the added stress can be devastating. Remember that the development of these resources is an 'ongoing process'; it cannot be 'accomplished'. In other words, parents should never stop adding to their knowledge, adding supporters, adding interventions, educating others, or advocating for their child in many areas. However, they should not burn themselves out trying to 'finish' the development of educational programs, interventions, and the like because these will naturally change as the child grows and changes. The goal is to always be moving forward, but acknowledging that taking a few steps backwards once in a while is natural and inevitable. Parents should not give in to panic because this leads to rushed decisions and poor long-term planning. This is a marathon, not a sprint – if the runner expends too much energy upfront in a nonproductive way, she will run out of steam before the end.

## **Grief**

There are phases of grief to be gone through, and different members of the family will react to grief differently. Sometimes, this becomes a problem in itself, since the different ways of coping might be incompatible. For instance, if one parent deals with the grief by expressing their emotions (needing to talk and cry), and the other shuts down and

prefers to remain in denial of the disability, this can cause additional stress on the entire family, including the disabled child and their siblings. Grief is an emotional state that flows through many phases, and everyone goes through them in their own time and in their own way. It is important to remain respectful of how others are dealing with grief. There will be times when you will feel you have conquered grief and it will surprise you when it returns from time to time, or you may need extra help to get through the sadness that can accompany grief. There is no right or wrong way, and no correct timetable. However, if a parent finds that they are not progressing in their grief, they should obtain professional help, because this can stagnate efforts to help the child (and the rest of the family).

## **Changing Roles**

The roles of each family member, as well as the family as a whole, will begin to change. Decide that the family will remain a team, and deal with the disability as a team, even though different members will be handling different roles. Communicate openly and be clear on those roles and the expectations (i.e. that siblings are not responsible for caregiving, or that both parents will attend Planning and Placement Team (PPT) meetings together), will prevent some of the misconceptions and fears that members may have. No one person should be overwhelmed with all of the roles, because there are simply too many, and one person should not be spread too thin. Resentment will surely build when one member feels they are overburdened with the expectations of the roles they fill. All parents of all children maintain roles such as: caregiver, disciplinarian, organizer, chauffeur, etc. However, to these already extensive roles, you must now add: therapist, advocate, teacher, counselor, any many more as the child grows and develops. Parents should be mindful that there are other equally important roles to fill, those of mother to the other children, spouse, friend, daughter-in-law, or neighbor and they should not be neglected. These are the roles that most often fall by the wayside because they do not seem as immediate or as critical, but loss of these connections will affect the rest of the family unit tremendously, and begin to break down the cohesiveness. Other people in your life - family, friends and neighbors - are your potential support system, and should therefore not be neglected. Family time, alone time, spouse time, and most importantly fun time, need to be included in schedules regularly, and sometimes this needs to begin fairly formally – writing time with siblings into the weekly schedule, or having a regular ‘date night’. Obtaining babysitters or other caregivers for respite is critical for parents to maintain the energy they will need over time. While it is sometimes difficult to find someone parents can feel comfortable leaving their child with, it is worth the effort to develop this resource, not just for the parents’ well being, but because those added relationships can sometimes be very positive ones in the child’s life.

## **Added Issues Within the Family Unit**

### **Spousal relationships –**

It is common for there to be disagreements about options, responsibilities, fears, resentments, or ability to handle stress or grief. Couples dealing with any life altering event, including the loss of a loved one, a change of home or job, or the discovery of a child's disability, experience added stress on a relationship that should be a supportive one. Many questions will come up that won't have easy answers. Does one partner need to quit their job to handle therapy and school demands? Who would be the caregiver? Who is the better negotiator to deal with schools, agencies and insurance companies? Who can drive siblings to activities when the child with autism requires therapy in the afternoons? How to deal with in-laws who have their own theories on meltdowns? How can parents deal with each other's opposite views on how to handle the child's anxiety? Communication and negotiation among spouses will need to remain open and non-critical of the other's strengths, weaknesses and approaches. Both partners are, after all, working in the best interest of the child. If resentments begin to fester, obtaining professional help from a therapist or social worker who is experienced with families handling disabilities may be a good decision.

### **Siblings –**

Siblings will have their own fears and insecurities to deal with (related to the disability or not), and it will be up to parents to help them through this as best they can. Parents can support them by being clear of expectations as a sibling, but also understanding that their feelings may not always be positive. They need to know, for example, that it's OK for them to feel embarrassed by their sibling sometimes, but that bullying or teasing because of it will not be tolerated. They may need assurance that they are just as important as their sibling, even if they feel they get less attention. 'Fair' doesn't mean 'equal' – 'fair' means 'everyone gets what they need'. Parents can reassure them by answering their questions honestly without giving them more information than they are able to handle at their age. Parents can add to their knowledge as they grow, and as they continue to ask more (because they will learn to trust that their questions will be accepted in an a respectful way). Likewise, parents should trust siblings enough to be honest when they are having a difficult day, but reassure them that it will pass, and everything will be fine. Obtain counseling from a professional if it becomes clear that they are struggling too much with the stress or the household demands. Be watchful for the signs of depression in any member of the family (including the one with the autism spectrum disorder).

### **Extended family members –**

Family who do not live day-to-day with the symptoms of the disability may have difficulty understanding and/or accepting the child with autism. Parents can help them by giving them basic information about how they can be helpful to both parents, the rest of the family, and to the child with an autism disorder. They may be very happy to be supportive, but be unsure of what to say, how to help, or fearful of doing or saying something wrong. Providing them with information about the individual child is more productive than loading them down with books on autism. It would, for instance, be helpful for them to know:

“John gets nervous when there’s too much noise, let’s find him a quiet place to go.”

“Mary doesn’t know how to ask for something she wants, so you may have to check with her from time to time.”

“Sean would love to tell you all about the lizards of the southwest – I understand it’s not a pleasant subject, but he’ll be much more calm afterwards, and then we can finish our chat.”

There will be times when family members will do and say hurtful things - most of the time without realizing it (though not always, depending on the family dynamics). They may not know that their comment was politically incorrect or even thoughtless, but parents should consider letting them know that whatever they have said or done was not acceptable and why. The family member may feel badly that they erred and try to correct themselves in the future, or they will, at least, be put on notice of topics or comments that are off limits. Parents should, likewise, accept that there are some people in the world who will simply never ‘*get it*’, don’t want to ‘*get it*’, and will never change their behavior. Energy spent trying to convince them of their error will be wasted energy. Being able to ‘let it go’ is a hard reality sometimes. Moving on and investing energy instead on the many people who will support, love, and help the family on their journey will be well rewarded.

## **Gathering Other Sources of Support**

Parents will meet many expected people along the way who are generally upbeat and accepting, and whom they might not get to know at all if their child were never diagnosed with a disability. Part of ‘acceptance’ means accepting the joyous things that come into your life. Apart from all the heartaches, there will be professionals (teachers, therapists, even camp counselors) that will awe you with their knowledge and respect for your child. There will be a neighbor whom you didn’t know until she returned your child one day when he went to ‘visit’ her cat, and who will become your best friend in life. There will be other mothers of children with autism spectrum disorders whom you can call when you need a shoulder to cry on, or advice on finding a new dentist who will value your business. Members of local support groups are invaluable in their

knowledge, and level of acceptance and understanding – seek them out. You will be put to the test sometimes, and just when you think you have nothing left to give, you will find the well is not as dry as you thought. You will learn advocacy and negotiation skills you thought you were way too shy for, and you will have many chances to develop your own self-esteem as you succeed in obtaining supports through a difficult process. These things will become important to you, and pieces of your life you will eventually look back on and appreciate.