

Getting through a diagnosis of Autism – How to support family members

Introduction

To some a diagnosis is the Holy Grail at the end of a long journey of convincing others that there are issues. To others it is an unwelcome visitor who remains forever. Whatever the response to the diagnosis, the impact upon the family's life is massive and has far reaching consequences throughout including:

- The family's amount of resources to meet the needs of the child with autism (funding for respite, therapy, damaged items, adaptive devices...)
- The number of children in the family
- The age differences of the siblings
- The existing kinds of coping mechanisms and interactive patterns within the family
- The family's life style
- The family's child-rearing practices
- The quality and quantity of resources in the community

Each member will react to the news in their own way, utilising a range of coping mechanisms requiring support whether formal or informal. So how do we support each person without intruding upon their lives? The following article will examine some of these support issues and how we can try to provide effectively for the family members.

How living with a person with a diagnosis of autism affects the family.

Parents – The keystone to the family

When a diagnosis of autism is made, the reaction of each person is different. I am sure those of you reading this will have experienced the full range of emotions such as relief, tears, surprise, devastation, helplessness and many many more. In some situations these can then turn into obsessions about seeking information on what could have caused the autism or what the future holds, or alternatively becoming

focused on ensuring that the child with autism develops in their life. Whatever the reaction and subsequent actions let no one say that it is the right or wrong way. Only you will know the best way for you to react. However amongst this grieving process being experienced by the family, it is important to consider all the family members and options available to each one.

Many of you reading this will be parents and especially mums. No this is not a sexist comment but based upon my own experience. Even in today's society the gender roles are still connected to work and child rearing. When a diagnosis of autism is made, these gender roles frequently become more apparent. There is considerable evidence that illustrate how mothers experience greater impact than fathers, much of this seems related to a difference in each parent's interpretation of the situation. Fathers tend to see the impact as less significant as the mother. It has been acknowledged that in some cases fathers develop a greater commitment to work resulting in long hours and so less active involvement with the everyday situation concerning their autistic child. In my experience, some comments from people have included that this is so the father does not have to acknowledge the issues. Also that by working so much and only being with the child at times when life can be "fun" they only see the better times. In this way fathers are able to see life through their rose tinted glasses. However before you accuse me of putting fathers down, during my many conversations with fathers over the years, yes in some circumstances this is true in many there is another side to it. Fathers do look at the impact in a different way to mothers, often in more concrete and practical ways, but they do experience an effect. This includes looking to the future for their child and how to provide for them as well as simple things like "losing" the child that they had dreamed of, notably if it is a son that they would have played football, etc.

In comparison, mothers have to deal with daily life having an autistic child and all that is involved with that. They become care co-ordinator, behaviour therapist, occupational and speech therapist, educator as well as providing for the rest of the family, all overnight. Professionals train for years to be just one of these yet we expect mothers to do this virtually overnight, and then wonder why the situation frequently collapses placing the whole family in a worse position. Simultaneously, mothers have to cope with their own feelings and emotions about the situation. Is it

any wonder then that mothers are more likely to report that their own emotional well-being has been severely affected by the situation. In fact research has found that over half of mothers with an autistic child had significant psychological distress associated with low levels of family support and with bringing up a child with challenging behaviour.

So how can both parents be supported and prevented from losing their sanity, as well as destroying their own relationship. Firstly any support, whether from family and friends or from professionals, must be proactive rather than reactive. This allows the support to be appropriate to the overall situation without placing additional problems upon the family. Remember children with autism need structure and planning to any changes in their lives, something which cannot be achieved if support is only provided in emergency situations. Of course there will be times when unavoidable situations will occur, but if strong plans are in place then the overall stress can be reduced.

Every parent tries to be a "super parent". Very often they do not want to ask for help because that means they cannot do it alone- and shouldn't they be able to handle this? While this may appear laudable, it is far from the truth. Having a child with autism requires help. Going it alone will ultimately completely stress the parents and family out. If they are stressed and overwhelmed it is not good for them or their child. Let's face it sometimes we all need help. As a parent of an autistic child, parents should feel able ask someone to help with the errands because very often it is too hard to take their autistic child out with them. However it should also be possible for family and friends to offer their support and services to the parents to avoid some of the embarrassment involved in asking for help. Remember getting someone to do simple tasks can help save parents from all the time and frustrations involved.

On a practical basis although parents want respite from the situation, often the overnight respite is not the ideal. This is the same for some of the home-based respite which frequently involves someone coming into the home and playing with the autistic child whilst the parents are in another room. Many parents have said that this actually increases the stress levels as the child, quite rightly, seeks to be with

the parent. Consequently any such support should aim to reduce this stress and provide actual need and not what is thought to be appropriate. This will then ensure that parents get the chance to get out or even just spend a quiet few hours at home. Remember everyone needs time to themselves and is not based on whether you are bringing up an autistic child or just living life. In the long run by helping parents to unwind and think about their own needs benefits the child as well.

Siblings – the children who live with the child with autism

As with parents, each sibling will react to the news of their brother or sister being diagnosed in different ways. This can often be dependent upon their own age and position within the family and includes resentment and rejection, embarrassment, anger, acceptance, supportiveness and loneliness. Being aware of these needs of and how they change over time ensures greater support for the siblings.

To illustrate this, the following is a selection of responses by siblings of children with autism within a workshop held several years ago in Ontario:

- lack of understanding as to how to deal with teasing
- embarrassment/anger when their sibling was teased and didn't understand
- a need to know more about the disorders and long term implications
- fear of acceptance when bringing friends into the home
- embarrassment to tell others that the autistic sibling is living in the home
- worry about the sibling with autism who may move far from home , and require long distance visits
- feeling responsible to protect the sibling
- not knowing what motivates the sibling or how/what he thinks
- sadness that the sibling is different
- anger at sibling's behaviours
- confusion—the parents think differently about the disorder
- a need to discuss more with parents
- a need to get away /take a break

- resentment regarding the time spent with sibling, or the money spent on the sibling
- resentment in having to do more chores, or clean up after the sibling
- resentment because more is expected of him/her
- fear of the sibling, fear of the future, fear of being isolated without friends
- desire for siblings to be able to play/participate

Sometimes the most difficult period for the sibling is when they are older than the child with autism. Imagine remembering a time when you had the full attention of your parents and then suddenly not only is there another child wanting attention, but they also require more attention than usual. Not only is there less attention available, but also your chance to go out and experience the world is limited because your brother/sister cannot cope with the noise or new places. Is it any wonder that many older siblings, when they reach an age when they can go out on their own, stay away so that they can gain more experiences. Of course the latter is not exclusively linked to older siblings, but the feelings seem to be greater when there are memories of the “good old days”.

These feelings are not solely linked with the older sibling. Even when there is no knowledge of life without a brother or sister with autism, younger siblings can develop a level of resentment toward the brother/sister. As with any family with more than one child, there are constant battles for parental attention. When one of the children has autism this battle becomes harder and often more physical. The sibling may feel neglected as they perceive that the autistic sibling is receiving preferential treatment. Consequently the occurrence of mimicking behaviours to gain attention, no matter how negative it maybe, can occur. Alternatively the sibling may over compensate for the situation by taking over parts of the caring role, something that should not necessarily be discouraged but also not encouraged to the point where they are doing adult tasks.

Emotionally siblings will have their own range of difficulties as well as questions which they may need answered in order to deal with these emotions but are afraid to ask. They need to be offered age-appropriate information which will need to be life-long about the disorder to the sibling without autism. Open discussion about the situation should be encouraged so that the children can be open and honest about

how they feel. These emotions can include the same guilt as experienced by parents but centred upon why they are healthy but not their brother or sister, or even the relief that they do not have autism. Also the guilt surrounding dislike of their autistic sibling who may be hitting or screaming at the parents whom they want to protect. They maybe afraid to verbalise these feelings or ask questions in case they upset their parents as well as not placing more pressure upon the parents by causing them worry. Consequently many siblings will keep these emotions and questions locked up deep inside of them with no way of venting their frustration. This can lead to loneliness and social embarrassment as the sibling lives a double life keeping their friends away from their autistic sibling.

Finally, the future. Many siblings will be questioning and worrying what this holds for them. How much responsibility will they have for ensuring that their autistic sibling is cared for when their parents are no longer able to or are not around. I have had many conversations with siblings of the children I work with in relation to this subject. Some have been 100% committed to caring for their brother or sister whilst others have been anxious about having to give up their future. Parents need to plan for the future .This lessens the pressure on the siblings and may also put into place services or people who will aid the sibling make decisions. It is important to have the siblings with the disability and their siblings at these sessions whenever possible. Some of the sessions could be held with several families present working together, while others may best be addressed on an individual basis.

Grandparents

Depending upon the family setting, often the extended family become an important part of the family's support. One in 166 grandparents will become grandparent to a child with autism. A review of empirical studies suggests that these grandparents experience significant role confusion. They provide the autistic child's parents—who are more likely to be depressed, single, or divorced—with both burden (e.g., conflict regarding behavioural symptoms) and emotional and instrumental support (e.g., childcare; financial assistance; advocacy). Frequently grandparents require similar

support and information to that given to siblings in order to provide them with a greater understanding of the situation.

Finally...

Although not every angle of support has been explored, some of the main areas have. As a final comment, support for each person is individual however it is a necessity to help ensure that the situation does not breakdown. Although many people in these situations may not come forward to ask for help, many still need it. So it is up to those around them to offer what they can no matter how large or small it maybe including directing them toward the light that is practical services and support..