



Finding your way with a child with special needs

From surviving to thriving

Being confronted with the fact that the own child has a developmental disability can cause enormous stress in parents and their families. Even though there are differences in coping strategies for everyone. According to literature and my own experience, it is normal that families/parents have adjustment problems with such diagnosis. Sometimes however, such a diagnosis might be a relief because they finally have something to deal with. Moreover, they get involved in reading the literature and start looking for new support systems. Others feel overwhelmed with all the extra work and treatment, which might be offered. In all cases the whole situation is seen as a traumatic experience for parents. The road from learning about the diagnosis to the acceptance that the own child has to deal with this disability for the rest of his/her life is hard.

Parents need a lot of patience, but also help in order to find a way to handle this challenging situation. They might go in a way through denial, resilience, blame, self blame, sorrow that all the expectation which were set into their child might be difficult or will never be fulfilled. The picture of being a “normal” family might feel as being destroyed. Certainly every parent wants to have his/her child beloved, being clever, successful and independent one day.

Additionally, self-blame often occurs because sciences do not explain clearly why these disorders develop. There is too much room for interpretation. Some people have the tendency to look too critically at their living arrangement or even genetic sources. This hypercritical view might lead to depression in the parents, as well. Apart from that, it makes of course a difference what level of diagnosis is given to the child. For example being confronted with a diagnosis of Autism Spectrum Disorder (ASD) –and again the severity of it has a big impact too– or Attention Deficit Hyperactive Disorder (ADHD), just to name two of them, has consequences on the daily life of a child and his/her family.

Furthermore, it is not always obvious how different the child is, because they are not all looking different in comparisons to other children. Therefore an outsider cannot see how much the child might struggle with some tasks. Parents can be confronted with friends and other family members who think they are giving too much attention to their child or worry too much about their child's achievements. Parents could be judged as being too worried or too ambitious and pushy to their children. This might also influence the parent's feelings and decisions. Although, in order to best help the child, it is very important to start as early as possible with a supportive education/intervention. In contrast to that every hesitation could cause extra stress in the child's daily life and affect the family life as well. Therefore, it is so difficult to find the right way in such a complex situation.



Ambiguous loss

In the literature, Pauline Boss, an educator of Child Development and Family studies, talks about ambiguous losses ([Boss, 2004, 2006](#)) what parents and family experience by living with a child with e.g. autism. The challenge with children with learning disabilities is, that there is no clear cut. Boss defines ambiguous loss into two categories, first the beloved person is physically absent but psychological present – this would be, when a beloved one, like e.g. a child cannot live with the parents (adoption, divorce of the parents, boarding school, foster care), or e.g. because of moving the social network is lost. The second case is, the beloved one is physically present but psychologically sometimes unavailable – this might be with a mental health problem which makes the individual emotional temporarily or always unavailable. The difficulties parents have to deal with from e.g. autistic children, is the uncertainty of the developmental path their child will take. The stage of the child might differ on a daily basis. Sometimes the child develops very well over a period of time and then falls back into a former or more difficult stage and all hope is gone again. Therefore it is challenging to find the right balance between acceptances of the child's diagnosis, which leads to the commitment of additional support. This should be combined with not giving up hope that additional education and intervention is useful. It is so crucial that all involved parties don't give up hope on the child.

Emotional Support

Experience in my own private practice showed how relevant it is for parents to find their own support system/group or someone to talk to about their doubts, feelings and anxieties, which they come across in their situation over time. Especially the feeling of not knowing how the coming day and future will look like might cause a lot of anxiety and stress in the mother or father. Naming the situation is often very helpful and the first step for the parents. It is important to acknowledge that it is the ambiguous situation, which causes the stress in oneself, and not once character. This might lead to a huge relief. The awareness that it is not one's own psychological health but rather the challenging situation, which is not always easy to deal with, releases a lot of stress. Therefore coming to this point helps to look more openly to new, more suitable, flexible family routines instead of remaining stuck and frustrated to old not useful routines.

*Angelika Matthias
Therapeutic Counsellor*

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