

“Living in a World of our Own”

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21 Manitoba parents of young children with autism described their lives as isolated, in a world of their own, just like their children are living in their own world of autism. The sources of parents' isolation were society's lack of understanding, isolation from a normal way of life, feeling disconnected from family members, and isolation from those in the service system. Recommendations to reduce this isolation included strengthening the service system to better meet the needs of the children and their parents.

This presentation described the results of a study that was designed to describe what it means to a family to have a child with autism. Through intensive interviews, the experiences of these families were recorded and the main ideas or themes were identified. Based on analysis of these interviews, recommendations were made that would help families both within the family unit and with interactions between the family and service providers.

Previous research on families and parents tended to focus on stress levels and coping strategies. This study looked instead at the “lived experience” of the families.

How was the study done?:

21 parents in 16 families (11 mothers-only and 5 mother/father groups) took part in interviews that took between 60 and 180 minutes. These parents were recruited through the MFEAT organization (Manitoba Families for Effective Autism Treatment). In all but one family, the ASD child was male, and the average age of the children was 7 years (range 3 to 9 years). All children except one came from two-parent households and all but two had siblings.

The parents were asked to describe their experience with very little prompting. This allowed the parents to talk about the issues that were important to them. The parents were instructed, “Please tell me what it is like to have a child with autism”.

Data analysis involved examining the transcripts and marking sentences or sentence clusters that depicted the main ideas, then these ideas were examined again until they could be reduced down to the essential themes. Essential themes are defined as experiences that are unique to parents who have a child with autism and are important to describe the overall experience of parents.

What did the study find?

By looking at the interviews and the field notes, the researchers were able to identify the essence of the parents' experience, as well as themes and sub-themes.

The 'essence' is the description that ultimately defined what it was like to be a parent with a child with autism.

The essence of these parents' experiences was "Living in a world of our own". Not only did the autistic children live in a world of their own, the parents/family were also isolated from family, friends and the society as a whole.

This isolation came from four main sources:

- **Society's lack of understanding** – lack of awareness of what autism was, lack of sympathy, and feelings of being judged (both the parent and the child)

- **Missing a "normal" way of life** – inability to experience normal family life experiences, particularly if the child's treatment was intense. One parent whose child was enrolled in the ABA program stated, "we have no life, we only have a program!"

- **Feeling disconnected from the family** – isolation was felt not only as isolation from the world of their autistic child, but also isolation/disconnect between spouses, with other children, and with extended family members

- **the unsupportive "system"** – the very system that was supposed to protect and advance the development of the child with autism was instead seen by parents as a source of isolation and frustration. The system was viewed as inaccessible, and the professionals who made up the system were often unsupportive, inexperienced, and had inadequate resources from which to draw.

The researchers summed up this experience as:

Overall, the product of the sense of isolation left parents with a diminished sense of hope. Parents expressed feeling completely defeated and on their own when they felt that family members, friends, professionals within the system, and others in their lives were not there to support their sense of hope that things would get better for their child.

Three main areas were identified to explain how parents attempted to deal with the isolation that they and their children experienced: Vigilant parenting, sustaining the self and the family, and fighting all the way.

1. Vigilant Parenting – this refers to the complete focus that parents have on their children, watching for their child's reaction and development and preparing how to react to their child's behaviour. In trying to manage their child's behaviour and interact with the 'system', the parents adopted strategies to help protect their child:

- Acting sooner rather than later: this refers to not letting opportunities to pass them by. The parents went to great lengths to get the treatment that their child needed in a timely manner, even if it meant being more assertive in demanding the treatment than parents were used to being.

- Doing all you can: Parents did not limit their child's treatment to one or two things, they were willing to try anything and everything to help their child reach his full potential

- Staying close to your gut feelings: Parents relied on their innermost feelings to determine if a therapy or service felt 'right' for their child or their family

2. Sustaining the Self and Family – this refers to the attempts parents make to bolster up their identity, to strengthen themselves and their family and to prevent the 'autism' from taking over their whole family.

To help sustain the parent and family, parents strove to work toward a healthy balance between the focus on their autistic child and the rest of their lives/family.

Parents also emphasized how important it was to cherish the milestones that their child did reach, even if it was later than other children. Also, rather than waiting for the 'big celebration', these parents tried to celebrate small improvements and steps along the way. This helped the parents to maintain hope and optimism for their child and his future.

Finally, parents said they needed to acknowledge and accept that there were certain things that they could not control, and not predict. They had to let go of some of the control, and to let things happen in their natural timeframe. They could not rush their child to develop faster than he was able, so they had to accept that and support him along the way.

3. Fighting all the Way – parents often felt at odds with the 'system'. They felt that the system was letting them down – not only their family but other families as well, and the parents were willing to fight for all the children and families facing the same situation.

Parents emphasized that, in trying to make the system work for them, they needed to be more direct (be assertive and clear in the treatment their child needs), to learn all they could (from books, other people, but especially from their own child), and to educate others (friends, family, and professionals).

Parents wanted others to realize that parents of children with autism try their best in raising their child and as such should not be judged or blamed for their child's behaviour. Parents expressed that professionals needed to be more receptive to both the child and the parent, and more importantly advocate with the parent in ensuring that the needs of the child with autism are met.

Recommendations

Based on the experiences described by parents, the researchers recommended that the greatest benefit to families would be a strengthening of the system that deals with their child. This includes all therapists, the school system, and any other individual responsible for the care of their child. The researchers recommended:

1. A Seamless system – that will

- make it easier for parents to connect to the appropriate professionals and support works (rather than having to search them out for themselves, so professionals are aware of other people to refer to)
- ensure consistency in care (so children are not having to get used to new people all the time)
- give parents options (find other ways to do things, not just sticking to one method)
- Prevent delays (provide service that is needed, when it is needed)

2. Listen to parents – take the concerns and recommendations of parents seriously

- not only give us the answers, but tell us what questions we should be asking
- communicate, communicate, communicate

3. Need professionals who specialize – not people who don't know what they are doing, or are learning along with the parent

4. Child vs. Family-centred care

- parents felt that, if appropriate and effective services were given to their child, that this would ripple down and benefit the family more than any treatment focusing on the family
- Treat the child like any other child
- Treat the family like a family

5. Respect the Parent – they know their child better than anyone, and professionals need to listen to the parents and acknowledge that parents are the experts on their own child

6. Help them succeed as parents – work with parents and give them what they need to succeed.

7. Realize and acknowledge to parents that they are **doing the best that they can** – do not judge

8. Help parents find that opportunity – help parents explore the options to treatment that will result in their child reaching his maximum potential

9. *Sustain hope* – don't give false hope, but encourage parents to look at small accomplishments and encourage them to support their child to accomplish more.

For more information on this study, and for copies of the presentation slides, contact Dr. Woodgate at Roberta_Woodgate@umanitoba.ca