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Parents Raising Adolescents Diagnosed With Low-Functioning Autism and Their Perceptions of the Level and Quality of Support They Receive

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Introduction

- Autism currently affects 1 in every 110 Australian children (Autism Spectrum Australia, 2009).
- Autism is characterised by: An impairment in social interaction, qualitative impairments in communication and restricted, repetitive and stereotyped patterns of behaviour, interest and activities (American Psychiatric Association, 2000).
- Individuals with low-functioning autism experience these symptoms in a much more severe form.

Introduction Continued

- Parents raising children with autism have been found to experience more strain and stress compared to both children without disabilities and also children with other disabilities such as Down's Syndrome (Hastings, et al., 2005).
- These parents need more support but are they getting it?

Aim of Study

- To determine the perceptions of parents who are currently raising an adolescent diagnosed with low functioning autism, with regards to the level and quality of support they receive from a.) The government and b.) The school in which their child is currently enrolled.

Research Design

- Interviews were conducted using open-ended questions.
 - The use of phenomenological analysis was employed.
- The present study included 20 participants, all of which were parents of an adolescent diagnosed with low-functioning autism.
- 18 women and 2 men.
 - Aged between 37 and 51 (M=47).

Procedure

- Participants were recruited through social networks and a snowball effect.
- These individuals then participated in an interview that lasted approximately 45 minutes. The interview consisted of open-ended questions designed to elicit responses that revealed the perceptions of the individual with regards to the level and quality of support they receive from both the government and the school system. All information received was to be kept confidential.
- All interviews were audio recorded for transcription purposes.

Findings

The results were analysed using a phenomenological approach. Five main issues were identified:

1. Isolation
2. Identity
3. Guilt
4. Fear
5. Hope

Isolation

Many participants felt particularly isolated as a result of a lack of financial assistance and a limited supply of resources and information.

For example one participant claimed:

Well, there's, I mean there's plenty. As far as being a parent, you're really in the dark. That's the whole thing. It's really just, if there are programs out there; communicate them and if there's no programs out there, they should, you know, I mean they... Somebody needs to help the parents because when you find out, you just don't know what to do, where to go. And it's very hard to try and find the right path to where you need to go, you know?

Isolation

Another parent reported:

But I, I sort of found that once the early intervention was over with, that was it! There's nothing else.... Yeh and so you're virtually left on your own to then manage.

Identity

Another common issue that arose for parents caring for an adolescent diagnosed with low-functioning autism was a feeling of a loss of identity. Many parents found themselves having to give up their careers in order to care for their child.

For example:

Umm, I'm a qualified teacher and if I was working I could be head of department. I had a promotional position and so at this stage I could be earning \$85,000 plus a year. I can't work because we have two children with special needs.

Identity

Another participant felt that she had been cut off from the world.

Lots of families when they have a child diagnosed with a disability, particularly a significant disability, they isolate themselves. For me, those two and a half years of doing early intervention three times a week plus a home session. I was non-existent to anybody else except my husband

Guilt

Many parents also appeared to feel guilty as a result of not being able to help their child.

For example:

Scott's favourite song is a Coldplay song which is Fix Me, you know I'll fix you, I'll help you, I'll do this for you, I'll fix you. It's like, it's pretty powerful coz it means they're aware. And being a mother you feel morally conscious and you know, responsible....and you feel guilty. You know what I mean? Well my thing is to restore Scott to full function by the time he's eighteen. I should have probably had it at a lower level but I had in my mind you know if I get him fixed by then.

Fear

Nearly every parent also voiced their concern about not knowing what may happen to their child, particularly if their child happened to be non-verbal.

For example:

But I worry that you know, if someone tried to take advantage of them, you know, how do they stop it? And you know that's the maternallness in me. So I don't really like the group homes, and also, their English isn't very good so... if this person like Johnny, has trouble communicating and umm, how's he gonna understand them if I can't and I've got nothing wrong with me?

Hope

Another issue that emerged when interviewing these parents was that of hope. It would appear that those who were given some sort of hope when they received their child's diagnosis, were more able to cope and hence adopted a more proactive parenting stance.

We were very lucky, when we moved here, we didn't know, Josh was diagnosed here and we were told by people "You're so lucky, out of all the places he could have got a transfer to, this was for Noah, the best place in Australia" because the Autism Association, oh because the not the Autism Association, the early intervention model here was, had the best reputation in Australia at that point, apparently.

Conclusions

- Society, in particular the government, needs to do more to support parents of adolescents with low-functioning autism.
- These individuals are raising our future so failure to provide them with the support they require may place the psychological well-being of multiple generations at risk.

Future Directions

- Future studies could explore the problems that currently exist with identifying one's position on the spectrum. Even individuals with the same diagnosis on the spectrum differ so much from each other and this makes it very difficult to ascertain what a position on the spectrum truly represents.

References

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