

Background

- Families with children with autism spectrum disorder (ASD) experience a **variety of difficulties** that range from the affected individual's challenging behaviors (Kelly, 2008) and health issues (Bauman, 2010), to factors that put strain on the family including stigma (Gray, 2002), providing for child's everyday needs, access to care (Farmer, 2013), financial burden, and worry about the future.
- **Understanding the needs of the families** will help researchers develop studies that are responsive to families and improve recruitment and retention efforts.

Objective

The goal of this study was to understand the perceived challenges facing children with ASD and their families with a view to developing relevant research priorities.

Methods

- Anonymous survey developed in Checkbox©
- Two versions: adults with ASD and parents of a person with ASD
- Results reported here are based on parents' responses
- August 1, 2014 to August 11, 2014
- Convenience sample recruited via emails to 23,000 Interactive Autism Network (IAN) Research registry participants and IAN Community e-newsletter subscribers, IAN Community website (www.IANcommunity.org), and IAN Facebook page
- A thematic content analysis (Marks, 2014) was performed to code two open-ended the questions on the survey:
 - If your **child** could get help for one autism-related challenge, what would it be?
 - If your **family** could get help for one autism-related challenge, what would it be?



Methods (cont'd)

- Responses were coded and categorized into themes and sub-themes. Some responses spanned more than one theme or sub-theme and were coded in multiple categories and, thus, coded responses total more than 100%.

Results

Parent-reported age of child:

- < 13 years – 46%
- 13-17 years – 29%
- ≥ 18 years – 25%

Key challenges for child (n = 888 responses)

- Social engagement/loneliness and isolation (24%)
- General behavioral issues (19%)
- Speech/language/communication (19%)
- Psychological co-morbidities/anxiety (14%)
- Engagement in enriching activities (13%)



Participant Responses

"Affordable and convenient opportunities for interaction with his peers where he can feel good about who he is and how he plays/interacts with others."

"To mitigate my son's severe language delay. It is ALL that I think about and work on. But I must confess it has beaten me down. It has drained all our resources, financially, emotionally and spiritually. He improves, but not at a pace that would lead to an independent life."

"Adult services for severely autistic young adults, a safe place to continue learning and socializing. Our Board of DD offers very little, and mostly to higher functioning adults. My son should not have to sit in a room and do "crafts" because he can not work, very demeaning."

"Dealing with meltdowns due to rigidity of thought and frustration"

"Helping my adult child deal with depression"

"Eating dinner together and eating the same food"

"Anxiety and insomnia symptoms dominate our lives (being on alert to manage the reality of a teen who leaves the house at all hours when anxious or not able to sleep)."



Results (cont'd)

Key challenges for family (n = 773 responses)

- Getting the help and services needed (18%)
- Financial issues (16%)
- General behavioral issues (15%)
- Family stress (15%)
- Transition to more independent living/issues of adulthood (15%)

Participant Responses

"What is going to happen to my son, who is 25, when I am no longer able to care for him?"

"RESPITE!!!! I don't know how my husband & I have stayed together all these years with the difficulties we've faced and continue to face without a break, but since my son's autism manifested we are continually on the breaking point."

"Behavior in public so that we could go out as a family" "Counseling to deal with stress on our family"

"Making everything more autism friendly. Restaurants, movies, malls, and schools."

"One of the greatest sources of stress for our family has been dealing with public education. So each year we endure the ignorance, lack of compassion and intentional dismissal of suggestions and it is just so hard."

Conclusions

- Individuals with ASD and their families face numerous and pervasive challenges. In addition to the expected concerns with behavior, communication, and co-morbidities, parents expressed deep apprehension about their child's isolation and meaningful integration into daily life.
- Parents reported that access to quality care, financial strain, and issues of adulthood, and their child's challenging behaviors were significant family stressors.
- Researchers and resource providers should take these challenges into consideration when designing studies and providing services.

References

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