Learning From Parents of Children with Autism Spectrum Disorder

Play Opportunities with Peers, Safety Concerns, and Effects on Parental Employment

Megan E Chen, MPH, Elizabeth Caronna, MD, Jon Rosenberg and C. Jason Wang, MD, PhD. Pediatrics, Boston University School of Medicine and Boston Medical Center, Boston, MA.
Autism Spectrum Disorder (ASD):
- Encompasses a range of mild–severe diagnoses
- The three major diagnoses are:
  1. Autistic Disorder
  2. Pervasive Development Disorder Not Otherwise Specified (PDD-NOS)
  3. Asperger Syndrome

All children with (ASD) display:
1. Impaired social interaction
2. Impaired verbal and nonverbal communication
3. Repetitive behaviors or interests
**Play Opportunities:** Children with ASD face significant barriers in creating and maintaining peer relationships. These relationships are often less interactive and more superficial than personal.

**Safety Concerns:** Ensuring safety for a child with ASD may be more involved than for a typically-developing child due to: language deficits, comorbidities of intellectual impairment, challenging behaviors (poor safety awareness, bolting, climbing).

**Effects on Employment:** Parents of children with a chronic condition are more likely to experience reduced employment, frequently due to the need to attend to their child’s medical needs. Average loss of income observed in families of ASD was recently quantified as 14% of reported income.
Research Questions:

- What are the challenges faced by parents in creating and maintaining play opportunities for their child?

- How do parents ensure safety for their child in the home and outside of the home, and what are the problems encountered?

- Has the child’s diagnosis affected parents’ employment or income? If so, in what way, and what are the strategies parents use to cope with these changes?
Methods

• **24** interviews with parents or guardians of children with ASD using three open ended questions related to the study topics

• interviews audio-recorded, transcribed verbatim, and coded

• Systematic analysis of data using standard qualitative data analysis techniques:
  1. identifying themes
  2. building and applying a codebook
  3. describing thematic characteristics, patterns and relationships.
Parent Demographics

Age

- 25-34 years
- 35-44 years
- 45-54 years

Gender

- Fathers
- Mothers
Education

- High school graduate/GED
- Some college or 2-yr degree
- 4-yr college degree
- >4-yr college degree

Race

- White-Non-Hispanic
- White-Hispanic
- Asian
- African-American
- Other
## Play Opportunities Themes

### Enablers

- **Child’s sibling is** “the best therapy we’ve ever had”.

- **Structure playdate to keep playmate interested:** “I try to make sure that I’m making it, you know, as fun for the typical child so that they want to come back. So we don’t lose a friend”.

- **Exposure to other kids:** “Introducing her and bringing her to certain places, so she can see how other kids play and interact”.

### Barriers

- **Child hardly notices sibling:** “It’s like I’m raising two single children.”

- **Intense therapy schedules:** “Sometimes the things that keep us from having play dates is actually his therapy schedule.”

- **Parent discouraged:** “Play dates are excruciating… sometimes he is so inappropriate that I just cringe”.

- **Other parents’ avoidance:** “He was getting in the way of the other kids… a lot of the parents keep their kids away. They don’t know what’s wrong. That was very hard for me”.

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# Safety Themes

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<th>Methods</th>
<th>Concerns</th>
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<td>- Basic childproofing techniques: “I never have to worry about little things as much with him”.</td>
<td>- Child inability to verbalize: “We’re not comfortable with her on the school bus… If something happened, she couldn’t tell us”.</td>
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<td>- Constant monitoring: “We have to keep an eye on him every step”.</td>
<td>- Influence of other children with ASD: “There was a kid… start banging his head against a table… she started to do a little banging of her head at home… and I’m like, no, no, that’s just not good”.</td>
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<td>- Visual aids and signs help with communication: “We have these all over the house, ‘No cards’… This has been a huge help with taking the stress out of the house”.</td>
<td>- Trusts limited number of caregivers: “We don’t trust babysitters… We just don’t feel we can put him in somebody’s hands that we can trust”.</td>
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## Effects on Employment Themes

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<th>Decreased work</th>
<th>Coping methods</th>
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| • **Parent present at therapy:** “It didn’t make sense from a therapeutic standpoint to have all these therapies when I’m not there”.

  • **School interruptions at work:** “I had to leave my job… mainly (because) the school was constantly calling my job to pick up my child”.

  • **Difficulty concentrating at work:** “General worry about what was going on, and I couldn’t focus on anything. So I stopped working, and I haven’t worked since then”.

|                                                                              | • **Work from home while watching child:** “It gives you so much freedom”.

  • **Change careers:** “I don’t particularly want to go back to marketing… I want to do (something) that might be of more use… an advocate”.

  • **Employer flexibility:** “My company has been so wonderful… They understand my circumstances.”
Conclusion

• Parents of children with ASD share many common issues in providing care for their children.

• Understanding these barriers as well as sharing coping strategies can help the development of effective interventions for families of children with ASD.
References:


