



Resource Article

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Engaging
Children with ASD
in Daily Routines

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Have you ever wondered if families of children with autism experience ridicule, that might impact their sense of dignity, when interacting with their child in public settings? To explore this question, Boyd and Goodwin (2019) conducted an interpretative phenomenological analysis (IPA) case study to explore family dignity in community-based experiences from the perspective of a family with a child with autism. Boyd and Goodwin (2019) explain that dignity is "...a fundamentally human state of being and refers to the quality or state of being honored or esteemed..." (p. 224). The researchers explain that dignity is often taken for granted until one is placed in a situation of vulnerability and its definition and meaning become more apparent (Boyd & Goodwin, 2019). The IPA was set to "...gain an in-depth understanding of how people make sense of and give meaning to particular personal and social experiences..." and to "...understand typical day-to-day lived experiences expressed by participants in their own terms..." (Boyd & Goodwin, 2019, p. 226-227). Data were collected over four months via semi structured and conversational interviews, and field notes. The participating family included Cole, a

six year old with autism, his parents, grandma and great grandma. The family was White, middle class, and resided in a large urban North American city. Their leisure activities included a wide range of indoor and outdoor activities, attendance at city events, trips to restaurants and shopping centers, use of public transit, and visiting with friends and family. Boyd and Goodwin (2019) explained that the family members experienced dignity along a continuum from the time of Cole's diagnosis at 2.5 years old until he was 6 years old. The authors highlighted four themes that emerged over the course of the study.

1. Living Under a Microscope

All members of the family shared the same experiences of community-based leisure activities; they remember feeling as though everyone's gaze was on them, feeling judged, and being singled out. The social exclusion that resulted from these feelings and experiences led to greater parental stress and a sense of loss of dignity. Boyd and Goodwin (2019) found that both parents also "reported experiencing violations of autonomy and their dignity, when their parenting was questioned by complete strangers" (p. 231). They both expressed attempting to protect Cole's

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sense of self during these experiences. When striving to protect Cole's dignity, his mother would attempt to make him blend in by modifying his expressions of happiness to avoid stares. She explained that when he was happy he'd begin flapping and other parents would remove their kids from him. She stated, "I think the worst part of it is when people don't want their kids to be around Cole" (Boyd & Goodwin, 2019, p. 232). Boyd and Goodwin state that "[t]he loss of dignity experienced through judgment and resulting humiliation requires considerable effort to restore within leisure contexts due to lack of control" (p. 232). While Cole's parents were increasingly aware of and concerned about the actions of others, both grandmas were less concerned. The grandmothers explained they simply focused on Cole and his enjoyment in the activity instead of focusing on the attention from others. They also reported not experiencing a loss of dignity for themselves or Cole.

2. Screw Your Microscope, We're Going Anyway

Boyd and Goodwin (2019) noted that overtime the parents learned to "...overcome the stares and judgment of others and engage unfettered in leisure settings as a family" (p. 233). The parents accomplished this by preparing everyone in the family for their outings and ignoring the comments or actions of others. To prep for outings the family made a list with Cole of the activities he could expect to see, do, and hear, and reminded him of regulation strategies. When preparation was not possible or successful, the family members would ignore comments and reject hostilities. Boyd and Goodwin (2019) explained that **by "[b]y** standing their ground in situations where their family was or had been mistreated, they challenged the moral stature of, and disrespectful interactions with, people in the community, and were able to regain self-respect, autonomy, and their dignity as parents" (p. 233).

3. Emerging Stories of Belonging

Even though the family has numerous stories of maltreatment by others when people were kind and

included the family it helped promote their sense of belonging. Cole's mother highlighted times when questions from strangers were from a place of caring or curiosity not judgement, and when people would make her feel less alone by explaining that their child does that too. Cole's father experienced social inclusion when people would interact with Cole in the community and when their community's physical environment supported their family's inclusivity. He recalled being at the local fair that had quiet rooms in various locations for families to take their children for breaks, this made them feel welcomed and included. The grandmothers both shared experiences where people would take the time to talk with Cole and answer his questions; this made them all feel a sense of belonging, including Cole.

4. Retreating, Feeling Overlooked, and Lamenting the Future

Boyd and Goodwin (2019) explained that "[a]s Cole began to communicate more and initiated conversations with strangers, the previous sense of Mom and Dad's dignity experienced through belonging, was replaced by Cole being overlooked, ignored, and dismissed by people" (p. 235). Cole's mother noted that as he got older the label "autism" was becoming his identity in the eyes of others. His parents recalled an experience when there was a sign on a bouncy house that read, "People with mental or physical disabilities cannot use the bouncy house", and this contributed to a loss in the family's dignity and increased social isolation.

As with many families who have a child with autism, their dignity is continually maintained, lost, and regained. Boyd and Goodwin (2019) explain that "... understanding how people experience dignity in leisure is paramount to the creation of open and welcoming environments in which all families can participate" (p. 237). The experiences of Cole's family helps raise awareness of the need for truly inclusive communities.

What do the data say?



How do parents of children with ASD address challenging behaviors?

Autism Spectrum Disorder (ASD) is “... neurodevelopmental impairments characterized by difficulties with communication, socialization, and rigid repetitive behaviors” (O’Nions, Happé, Evers, Boonen, & Noens, 2018). Problem behaviors such as self-injury, running away, aggression, property damage, inappropriate behavior in public, extreme irritability, and persistent non-compliance with everyday demands are common in children with ASD (O’Nions et al., 2018). O’Nions et al. (2018) highlighted parents’ reports that problem behavior is typically associated with changes in daily routines, feared stimuli, anxiety related stressors, distress, and attempts to escape. While much is known about helping parents address challenging behavior, little is known about how exactly parents manage their child’s challenging behaviors (O’Nions et al., 2018). This meta-synthesis examined 15 case studies, 8 case series, and 50 studies to learn about parents’ spontaneous methods for managing challenging behaviors (O’Nions, 2018). The focus was on parents managing challenging behavior, irritability, non-compliance or avoidance of demands, and anxiety. The following nine concepts were identified as parenting strategies used in response to the behaviors of their child with ASD.

1. Accommodating the Child

O’Nions et al. (2018) stated that “[p]arents reported adapting routines to accommodate the child by following the child’s ‘unique rules’ for how things should be done”. Parents expressed that this included indulging the child’s preference for sameness, for example, providing them with the same meal each night or practicing the same routine and sequence of events each day. Accommodating the child to avoid problem behaviors also included avoiding doing things that the child did not like. O’Nions et al. (2018) cited Lucyshyn et al. (2004) describing how one parent avoided provoking their child with ASD by not talking to their older daughter when the younger daughter, with ASD, was present. Parents also gauged their child’s energy level and mood, if their child had a tough day they would reduce demands, adapt behavioral

goals to be more achievable, and give extra time to complete tasks.

2. Modifying the Environment

Another parent approach to reduce problem behaviors was limiting their child’s exposure to sensory stimuli that could trigger problem behaviors. Parents reported actively avoiding places, events, foods, items, and activities that their child found difficult. One parent shared that they rarely went out together as a family, so that one parent could stay behind with the child with ASD to reduce the risk of an outburst or behavior that others might find distressing and to accommodate the child’s preference for sameness.

3. Providing Structure, Routine and Familiarity

To reduce the likelihood of their child encountering unexpected stimuli parents reported sticking to fixed routines (O’Nions et al., 2018). Routines helped the children with ASD transition from one activity to another and reduced the risk of problem behaviors. Parents explained the importance of using picture schedules or lists with their child so they knew what to expect. Parents also stressed the importance of providing their child with advance notice and long conversations about possible changes in their routine. Parents reported striving to keep things as predictable and familiar as possible.

4. Managing Non-Compliance with Everyday Tasks

Parents reported that when their child with ASD refuses to complete a task, such as getting dressed in the morning, the parent often intervened to assist the child. This reduced the performance demand placed on the child but decreased the risk of a related problem behavior. Because of this strategy, some parents reported doing everything for their child in order to avoid problem behaviors. Other parents expressed giving their child repeated visual and physical prompts to complete tasks, linking activities to the child’s special interests, tricking the child, gently coaxing, or giving choices as strategies to facilitate completion of everyday tasks (O’Nions et al., 2018). The use of reward systems, bargaining, and praise were also common strategies practiced.

5. Responding to Problem Behavior

Some families reported using distraction as a tactic to divert problem behaviors. Distraction typically involved a must have item for the child, which many families indicated was often a hand-held electronic device (O’Nions et al. 2018). Devices were also used in the home to pre-empt problems and give family members some free time (O’Nions et al., 2018). Other responses to problem behaviors included ignoring, explaining what is appropriate behavior, telling the child “no”, giving verbal reprimands, removing privileges, and giving punishments. Less frequently, responses to problem behaviors included time outs, parents shouting and yelling, and physical punishment.

7. Managing Distress

In order to manage a child’s extreme distress such as outbursts and/or meltdowns many parents reported they attempt to comfort their child by providing verbal or physical attention and additional sensory activities. Parents also indicated they would remove the child from the situation that was causing them distress or ask others to leave.

8. Maintaining Safety

In order to prevent destructive and dangerous behavior or elopement, parents would physically contain the child. This included keeping doors locked and installing motion detectors or other security features so that the child couldn’t leave the house unnoticed (O’Nions et al., 2018). In order to reduce aggression and injury to siblings, parents would often keep the child in a different room. Parents would also use physical restraint to manage aggressive or dangerous outbursts and to prevent injury to siblings or themselves.

9. Analyzing and Planning

O’Nions et al. (2018) reported that parents attempted to “...anticipate problems that the child might have in a situation”. Parents also reported thinking about what caused a problem behavior in order to “...develop a more strategic response” in the future (O’Nions et al., 2018). O’Nions et al. (2018) cite Schaaf et al. (2011) who quoted a parent sharing “I have to [be] two steps ahead of him every waking moment when I’m not here in this house... I have to plan ahead every step of the way... there is always going to be a meltdown, something he doesn’t want to do”. To prep for outings parents expressed the importance of making a contingency plan.

O’Nions et al. (2018) state “[a] key finding of this synthesis is the significant complexity of parenting strategies to manage and pre-empt problem behaviour, and the unrelenting burden that meeting the child’s requirements presents”. The findings reported in this article highlight the complex parenting demands of having a child with ASD. This research also highlights the extent parents go to promote their child’s positive behavior by adapting situations, demands, and requirements to support the child and avoid direct challenges (O’Nions et al., 2018). O’Nions et al. (2018) cite Lucyshyn et al. (2004) who stated that a parent’s main goal is to preserve the family unit and “...making concessions is perceived to be the lesser evil” to accomplish this goal. The results of this analysis highlights the need for increased understanding and responsive intervention to build upon what families are already doing and to further support families to facilitate their child’s successful and enjoyable participation in day-to-day activities, interactions, and routines.

O’Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018). How do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis. *Journal of Autism & Developmental Disorders*, 48 (4), 1272–1286. <https://doi-org.proxy-su.researchport.umd.edu/10.1007/s10803-017-3361-4>



Consultation Corner

Running Errands and ASD

Dr. Hedda Meadan

Running errands such as going to the store, the bank, and the mall are common in every family daily routine. Running errands are important for all families to complete needed tasks like buying food and paying bills. For young children these day-to-day errands can also help build social relationships and increase diverse experiences with new places and new people. Running errands with young children provides them varied opportunities to learn important skills such as social skills and daily living skills.

However, running errands could be challenging and stressful for many families with young children with autism. The primary characteristics of autism of deficits in social communication and interactions, and restricted, repetitive patterns of behavior can make running errands with young children with autism challenging. In reality, the challenges can be so significant that some families with children with autism may avoid going on errands because of concerns related to (a) children's challenging behavior and meltdowns that could interfere with completing the errands, (b) feeling of embarrassment in public places due to children's behavior, and (c) safety for their children and fear of children wandering or running away.

There are different resources to support parents and professionals when planning and going out to run errands.

[Autism Speaks](#) developed resources to [support community integration](#) and [Sesame Street](#) describe ideas for preparing for outings. In addition, [the Marcus Autism Center](#) describe safety tips for families with children with autism.

Professionals can help parents in planning and going out to run errands by partnering with the parents and discussing the following steps:

1. Identify errands to do with the child with autism.
2. Discuss potential challenges during the outing and ways to address these, especially safety concerns.
3. Prepare a bag with preferred toys, snacks, and items that could help the child in the new environment (e.g., visuals, noise cancelling headphones).
4. Use visual supports to prepare the child for what to expect on the errands.
5. Plan to go on errands during times that are best for the child (e.g., child is not tired or hungry) and times in which the setting/location is not too full, noisy, or require a long wait time.
6. Take small steps when going out to run errands (e.g., go out for a short visit to the setting, shop at a small store instead of a large mall).
7. Teach skill during outing (e.g., how to greet, ask for help) and remind child of expected behavior and tasks.
8. Remember to praise and reinforce the child before, during, and after the errands.



On the WWW

The web resource this month is a set of travel tips for families of children with autism. The link, from Milestones Autism Resources (www.milestones.org), provides evidence based information to help improve the lives of individuals with autism.

The travel toolkit includes tips to help minimize stress associated with traveling. The following topics are included:

- Planning the trip
- Medical and Safety Concerns
- Getting Ready to Go
- Airplane Travel
- Using Social Stores
- Road Trips
- Apps for Entertainment

Check out the link to learn more.

<https://www.milestones.org/resources/tool-kits>



Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for KIT readers.

In line with the focus on **Engaging Children with ASD in Daily Routines** readers are invited to receive continuing education contact hours for reading the monthly KIT publications (December 2019 - February 2020) and completing a multiple-choice exam about the content covered in these KITs.

KIT readers will receive the exam for this series in February 2020. There is no need to register for the CEUs. Rather, if you are interested, complete the exam online at www.edis.army.mil

Upon successful completion of the exam, you will receive a certificate of non-discipline specific continuing education contact hours.

KIT Newsletters
are online at
www.edis.army.mil

Thank you for your continued interest in the KIT.

