Utilization of Special Care Plans in Audiology for Children with Autism Spectrum Disorder

A Literature Review

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Introduction

Autism and Audiology:

Children with Autism Spectrum Disorder (ASD) are often seen in the audiological setting for hearing evaluations to better understand their communication abilities. ASD is characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors; although, these characteristics vary in severity and presence across children with ASD. In addition, "Children who are diagnosed with ASD often have difficulty with transitions and change and show hyper- or hypo-reactivity to sensory input, including auditory input." (8) It is crucial to understand the child's hearing abilities, to better understand their communication needs and potential. As a result, many children with ASD require audiologic management or testing. In a study done by Tomchek and Dunn in 2007, it was found that, "58-79% of children [with ASD] had abnormal auditory filtering, difficulty attending to auditory stimuli, were distractible or could not function in noisy environments, and were unresponsive to auditory stimuli" (8) The skills these children struggle with are skills necessary for real world listening. Being able to better evaluate and understand their skills will allow for more individualized care and follow up. Therefore, evaluation of hearing and thorough audiologic testing is necessary to increase beneficial care for children with ASD. Hearing evaluations encompass numerous tasks and elements that may be difficult or overwhelming for children with ASD to participate in and tolerate; often hearing evaluations can be a complicated and stressful experience for children with ASD and their families. Preparatory work by clinicians and families, and partnership with care givers and families has potential to create more individualized and increased quality of care.

Pertinent Statistics:

"Children with special health care needs make up 15-20% of all US children" (10)
"40% of children with hearing loss have other developmental disabilities" (3)
"82% of children with ASD have co-existing developmental disorders" (6)
"1-4% of children who are deaf or hard of hearing also have a diagnosis of ASD" (7)

In a questionnaire for children with ASD, hearing was rated as a sense that is affected most in the classroom (88% reported trouble with hearing) (5)

Table 2 The participant's scores from the questionnaire rating how much each sense affects them in the classroom

	Senses			
	Hearing	Touch	Smell	Vision
No. of participants affected by the sense[a]	14	12	7	9
Percentage of participants affected by the sense	88	75	44	56
Means, ranges and standard deviations	$M = 6.18$ (1–9)	$M = 4.88$ (1.5–8)	$M = 4.29$ (1–10)	$M = 4.06$ (1–9)
	$SD = 2.90$	$SD = 2.26$	$SD = 2.98$	$SD = 2.70$

[a] Out of a total of 16 participants

ASD and test performance:

Children with ASD react differently to the presence of observers than their typically developing peers. Chevallier et al. (2014) explain that typically developing children are facilitated by and perform better when tested by social interaction than by computer-based programs. Children with ASD do not perform better (or worse) in the presence of an observer when compared to computer-based programs. (2) Children with ASD do not benefit from a human tester, but rather perform at same levels with and without human contact. This supports the need to better understand motivating factors for children with ASD in order to better facilitate audiologic testing. In another study by Grove, Roth,and Hoekstra (2016), the authors found that children with ASD scored higher for intrinsic factors and motivation. (4) This finding suggests children with ASD are motivated to perform due to excitement and enjoyment. Special interests of children with ASD were related to positive affect and intrinsic engagement rather than alleviating negative emotions. Understanding these special interests and incorporating them into hearing evaluations could facilitate and improve testing for individual children.

Parent Perspective on Audiologic Testing

Families of children who are Deaf or Hard of Hearing with an ASD diagnosis were surveyed in a study by Wiley, Gustafson, and Rozniak (2013). The authors found that families indicated continuous use of non-motivating reinforcers during audiologic evaluations, due to the fact that clinicians did not ask the family for input. (11) Need for routine and preparation were huge factors for families, and were primary concerns for parents prior to testing. Families also indicated that clinicians should indicate why they are doing testing, even if it is to push limits and define strengths and boundaries. Families wanted to be more involved in their child's care, and preferred to be seen as partners in the appointments.

Special Care Plans in the Hospital Setting

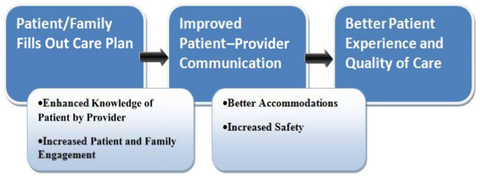
"Studies show that general pediatricians do not feel adequately prepared to care for children with ASD" (9)

"[Providers had] lower overall self-perceived competency in caring for children with ASD compared with children with other neurodevelopmental conditions." (9)

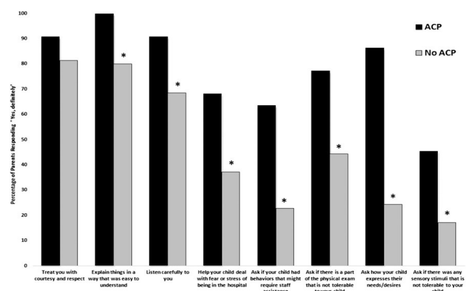
An Autism Care Plan (ACP) was created in one study for children being admitted to the hospital. (1) The ACP was added to the electronic medical record and tracked every time a professional caring for the child used it. All patients with ACPs had their ACPs accessed on day one of their hospital stay. "The majority of parents (88%) reported that the ACP 'definitely' improved their hospital experience compared with not having an ACP." In fact, parents of children without an ACP reported poor overall experiences, which may be a trend for this population. The use of ACP's could increase quality of care for children with ASD, as currently care may not be at a level parents and families find beneficial. Increasing knowledge of a patient's ASD might also alleviate some provider's concern in regards to competence in care of these patients and lead to better patient and provider experiences.

Respondents report that ACP is easy to administer, and took roughly 10 minutes to complete. Filling out the ACP might help families prepare for hospital stays better, as it also introduced many elements the caregivers had not thought about or expected in terms of the hospital experience. "Care plans hold promise to improve the experience of care during hospital admission for patients with ASD and their families."

Expected Outcomes with ACP



Actual Outcomes with ACP



Potential for Special Care Plans in Audiology

Types of questions that could be included in the Special Care Plan:

- Does your child get distressed, anxious, or overwhelmed in health care environments?
- How does your child respond to medical visits or hospital admissions?
- How does your child indicate that he/she is getting upset?
- What strategies have been previously used to manage behaviors that are a negative response to care or environment?
- What known anxieties or sensory sensitivities does your child have?
- What calming techniques (toys, music, sensory input) does the child or family have?
- What is your child's preferred communication mode?

Special Care plans should be obtained prior to the appointment, in order to initiate a proactive approach to specialized care, rather than a retroactive approach. This should create better overall care and better overall family and patient experiences.

Use of Visual Schedules and Social Stories

Visual schedules and social stories should be provided to families prior to their audiology appointment or at the time they create a Special Care Plan. Pictures for the visual schedule and social story can include images of the clinic, audiologist, equipment and rooms the child will encounter. These strategies will help the child and family better prepare for the appointment. Pictures can be provided of specific audiology staff that the child will meet.

"A picture chart is sometimes introduced during therapy with [children with ASD] and then incorporated into the child's routine at home. Visual aids are often used to support communication with [children with ASD]. Studies and anecdotal evidence have shown that children with ASD are better able to process visual tools than verbal communication" (Autism Speaks, 2013a, b; Bryson et al., 2003).

Social stories can encompass the entire appointment, from leaving the house to walking out of the hospital or clinic.

Parent and Health Care Providers Report

Parents' Report of Needs:

Parent and health care providers differ in their explanation of behaviors of children with ASD in the hospital and medical settings. In a study done by Johnson et al. (2013), health care providers reported attributing a child's challenging behaviors as self-stimulation and aggression, whereas, mothers attributed this to child's communication frustration, hyperactivity, and self-calming. (6) In this study, the collaboration of parents and providers was stressed and encouraged to create environments that could ease stress and anxiety of both children and families. Parents in this study reported wanting to be seen as partners in their child's care.

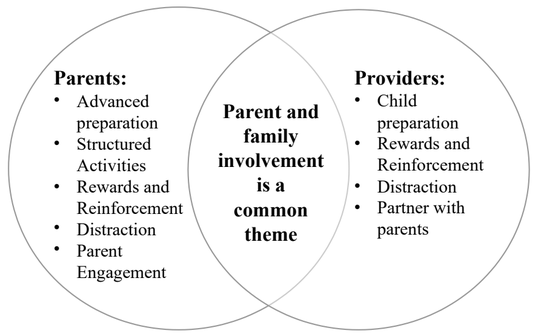
Focus group of mothers of children with ASD concluded in two major themes: "HCP's just don't get it" and "Families felt marginalized by people who should care most". Parents also explained that hyperactivity in hospital could be due to the fact that self-calming behaviors are not available to their children. (6)

BOX. Focus group question guide

A. Parents
1. What was the behavior pattern of your child before you went to the hospital?
2. What was the behavior pattern of your child in the hospital?
3. What was the behavior pattern of your child once you returned home?
4. What strategies did you use before the child came to the hospital?
5. What strategies did you use when the child was in the hospital?
6. What strategies did you use once the child returned home?

B. Health care providers
1. What was the behavior pattern of the child in the hospital?
2. What strategies did you use before the child came to the health care setting?
3. What strategies did you use when the child was in the health care setting?

Attributed Meaning of Behaviors of Children with ASD in the Hospital Setting: Possible Strategies to Better Facilitate Families and Patients



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