Many parents spend years seeking answers for their child’s developmental and communication delays and concerning behaviors. Although early intervention is associated with improved outcomes, parents are not able to access interventional services until a diagnosis is accessed. Factors that affect age of diagnosis remain unclear.

Autism Spectrum Disorders

Characterized by:
- Verbal and nonverbal social communication deficits
  - Reciprocity
  - Following rules for conversation
- Forming and maintaining relationships
- Restrictive and repetitive patterns of behavior and movements – intensive interests
- Rigidity adherence to routines
- Hyper- or hypo-reactivity to sensory input

Questions:
1) What is meant by “challenging behaviors”?
2) What are parent challenges of caring for their child?
3) Access challenges
4) Parent decision-making
5) Use of interventions at home and in public

Sample
- Ethnically, SE and educationally diverse sample
- 42 parents of children with ASD
  - 16 (38%) parents completed a paper and pencil survey
  - 26 (62%) parents completed an email version of the same survey

Synthesis of Literature

Stress and Parents of Children with Autism Spectrum Disorder

Findings
- 1:68 children in the US are diagnosed with ASD
- Their parents measure higher level of stress, anxiety and depression than other groups of parents
- Stress is attributed to their child’s challenging behaviors
- Parents struggle to access an ASD diagnosis for their child
- Parents feel disrespected and disregarded by HCP who attribute the child’s challenging behaviors to poor parenting
- Factors associated with age of ASD diagnosis are unclear:
- Parents of color attribute their experience to racial discrimination; AA and Hispanic children receive later diagnoses for similar symptomology
- Children from lower SE and rural areas receive later diagnoses
- Parents are not able to access treatment or strategies to learn how to manage their child’s care until a diagnosis is received
- Early intervention is associated with improved social communication, improved brain function and lower need for costly services as the child develops

Sample
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**Sample Description (N=42)**

<table>
<thead>
<tr>
<th>Child's current age</th>
<th>%</th>
<th>Range</th>
<th>Mode</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3 - 5 y</td>
<td>9 y</td>
<td>3 y</td>
<td></td>
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</tbody>
</table>

Gender
- Male: 62%
- Female: 38%

Diagnosis
- Autism / ASD: 19%
- Asperger's / HFA: 12%
- PDD: 5%
- Other (Ring 22): 5%

Respondent
- Parent: 93%
- Grandparent: 7%

Race/Ethnicity of person with ASD
- Caucasian/European American: 74%
- Other: 26%

Race/ethnicity of parent/guardian
- Caucasian/European American: 81%
- Other: 19%

Parent/Guardian educational level
- Less than college: 40%
- College degree or more: 60%

Total household income before taxes
- Less than $75,000: 57%
- $75,000 and more: 43%

**Seeking a diagnosis**

- Parents spent 0-10 years seeking a diagnosis
- Parents talked to HCP 0-13 times before receiving a diagnosis
  - 1 received a diagnosis prior to expressing concern
  - 1 reported talking to the HCP ‘1000 times’
- Pediatrician most often made referral for diagnosis (14%)
  - Family practice physician (5%)
  - Psychologist (7%)

**Age of diagnosis**

- Age of diagnosis 2-30 years of age
- Psychologist most often made diagnosis (67%)
- No significant difference between ethnicity and age of ASD diagnosis

**Length of time seeking a diagnosis**

Length of time seeking 0-10 years (t=1.4; df=31; p=.144)

- Caucasian parents (19)
  - 63% expressed concern prior to diagnosis
  - 37% were diagnosed at or near time of diagnosis

- Other parents (23)
  - 50% expressed concern prior to diagnosis
  - 40% expressed concern at diagnosis
  - 10% expressed concern after diagnosis

No significant difference between ethnicity and length of time seeking a diagnosis

**Results in review**

- Analysis revealed parents visited their child’s healthcare provider 3-30 times while seeking an ASD diagnosis over a period of 2-10 years:
  - Age of diagnosis ranged from 2-30 years of age
  - Wait times ranged from 0-10 years
- Pediatricians made a majority (14%) of referrals for ASD diagnosis
- Psychologists made a majority (67%) of ASD diagnoses
- No significant differences were found between:
  1) ethnicity and ASD diagnosis
  2) ethnicity and length of time parents spent seeking a diagnosis
This is a highly educated, ethnically diverse sample of respondents. Yet parents still struggled to access a diagnosis for their child.

Several factors need to be explored:
- Parental and cultural responses to developmental and communication delays
- Additional demographic factors, such as geographic location and sex of child
- Availability and overload of existing resources
- Primary HCP knowledge and awareness of ASD (Pediatricians, Family practice physicians, nurse practitioners, psychologists, neurologist)
- HCP attitudes about ASD
- Parent communication with healthcare providers
- Parental response to the ASD diagnosis

Implications:
- No child should be denied the services they need to adequately function and to achieve their full potential

At any given time, 55% of children who exhibit autism spectrum disorder (ASD) characteristics are not receiving the services they need.

One of the reasons is because they lack the necessary diagnosis that is the gateway entry into interventional services.

Only 37.5% of the children who are not receiving services for their special needs have actually been diagnosed (Russell, Ford, Steer, & Golding, 2010).

These impressive statistics indicate that the reported 1:68 children prevalence of ASD is severely underestimated and a considerable number of children are neither diagnosed nor receiving much needed services.

Children who participate in early interventional services exhibit improved social and communication outcomes, improved brain function, and lower need for costly services later on.

Implications
- Knowledge of ASD can assist HCP in preparing for the care of children and their families and in being supportive of parental concerns and needs
- HCP who are knowledgeable and supportive can facilitate earlier referral, diagnosis, and entry into interventional services

How does this knowledge affect every nurse?

1 in every 68 children are on the autism spectrum ... At least that many of your patients and research participants are on the spectrum

Understanding parents’ stories and the challenges they experience help us as nurses and health care providers to develop unique and individualized approaches to meet their needs.