

Parent Experiences Seeking an Autism Spectrum Disorder Diagnosis and Services

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Autism Spectrum Disorders

(APA, 2013)

Characterized by:

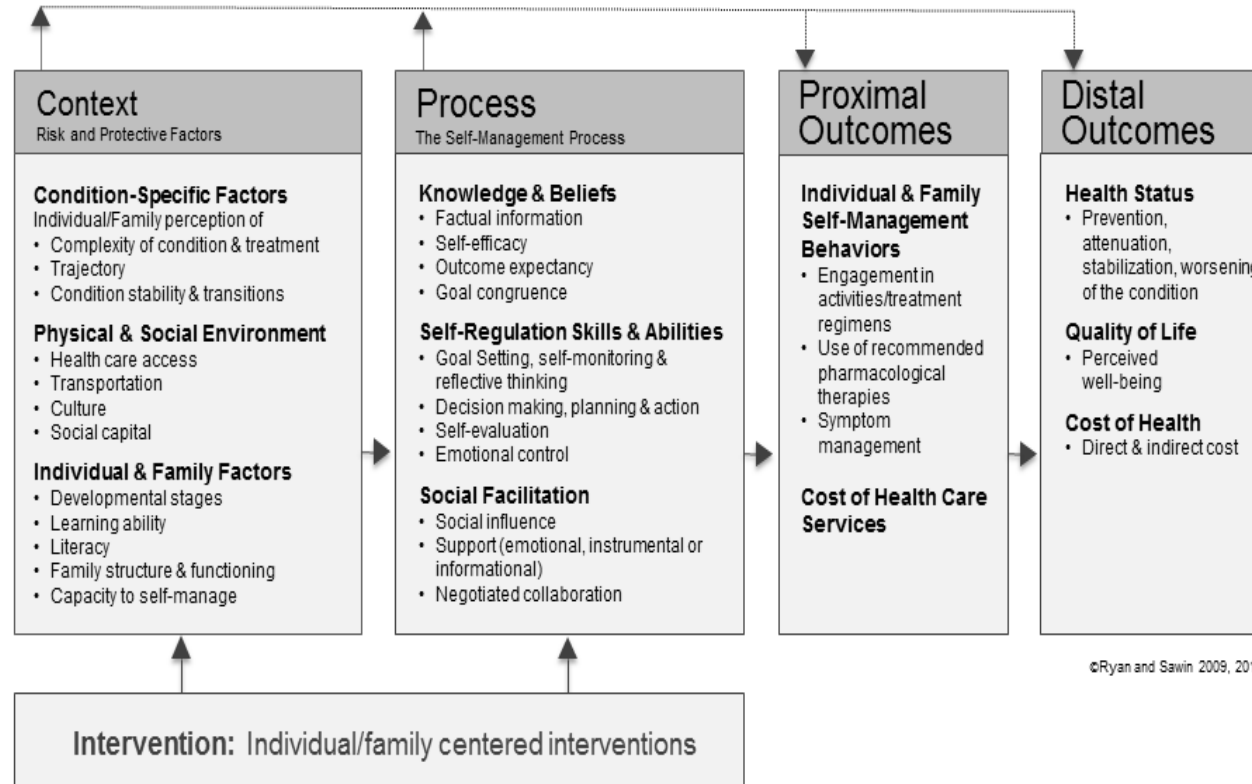
- Verbal and nonverbal social communication deficits
 - Reciprocity
 - Following rules for conversation
- Forming and maintaining relationships
- Restrictive and repetitive patterns of behavior and movements – intensive interests
- Rigid adherence to routines
- Hyper- or hypo-reactivity to sensory input

5-Part process

1. Review of literature
2. Survey: Access to diagnosis and services
3. Focus group/individual interviews: Access to diagnosis and services
4. Focused interviews
5. Application
 1. Knowledge and attitudes
 2. Policy and budget

Stress self-management for parents of children with autism spectrum disorder

Individual and Family Self-management Theory



1) Review of Literature

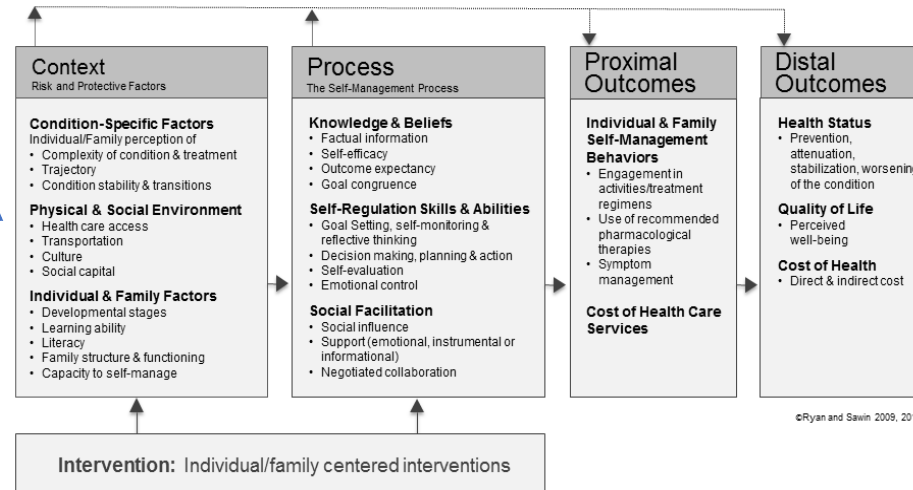
Stress and Parents of Children with Autism Spectrum Disorder

- 1:68 children in the US are diagnosis with ASD
- Greater than 80% of the 2 million parents of children with autism spectrum disorder (ASD) report they feel “stressed beyond their personal limits” (Bitsika, et al., 2009, p. 540)
- Parents of children with ASD score higher levels of stress, anxiety and depression than
 - parents of children without ASD (Bitsika, et al., 2009; Totsika, et al., 2011).
 - parents of typically functioning (TF) children (Baker-Ericzen, 2005; Dabrowska, et al., 2010; Hayes, et al., 2012; Montes, et al., 2007; Pisula, et al., 2010; Rodrigue, 1992).
 - children with Down Syndrome (Dabrowska, et al., 2010)
 - children with other disabilities (Reed, et al., 2013).
- Stress is attributed to their child’s challenging behaviors (Lecavalier, et al., 2006) - Characteristics of those behaviors are not clearly described in the literature (Falk, et al., 2014)
- Efficacious programs – parents continue to measure high levels of stress

Review of Literature

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Factors that affect access to ASD diagnosis remain unclear



Synthesis of Literature: Access

HCP

- Parents feel disrespected and disregarded by HCP who attribute the child's challenging behaviors to poor parenting (Altiere, et al., 2009a; Nealy, et al., 2012; Silva, et al., 2012)
- Some parents believed HCP negative attitudes and lack of knowledge contributed to delayed diagnoses and referrals for their children (Brown, et al., 2010; Nealy, et al., 2012; Silva, et al., 2012)

Disparity

- Parents of color attribute their experience to racial discrimination (Altiere, et al., 2009a; Gray, 2006)
- Findings mixed:
 - AA and Hispanic children receive later diagnoses for similar symptomology (Fountain, 2011; Harstad, et al., 2013; Liptak, et al., 2008; Mandell, 2009; Rosenberg, 2011; Shattuck, 2009; Valicenti-McDermott, 2012)
 - No difference between ethnicity and age of diagnosis (Golin-Kochel, 2006; Myers, et al., 2009; Perryman, 2009)

Gender

- Prevalence in 2010 **1:68**
 - 1:42 boy
 - 1:189 girls (Balo, 2014)

Education

- Higher level of parental education
 - More likely to seek professional assistance
 - Better prepared to communicate with HCP
 - Collaborate in developing a plan of care (Harstad, et al., 2013; Mandell, et al., 2009; Rosenberg, et al., 2011; Valicenti-McDermott, 2012)
- Higher level of maternal education – fewer barriers to access to diagnosis and services (Hidalgo, et al., 2015)

Talking with parents elicited more information and questions

2) Survey: Parents of children with ASD

Age of ASD diagnosis and length of time seeking diagnosis and services

Sample Description (N=42)

Ethnically, SE and educationally diverse

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

	Range	Mode	median	%
Child's current age	11y	13y		3 - 37y
Child's age of diagnosis	3y	6y		2 -3 y
Gender				
Male				62%
Female				33%
Diagnosis				
• Autism / ASD				19%
• Asperger's / HFA			12%	
• PDD				5%
• Other (Ring 22)				2%
Respondent				
• Parent				93%
• Grandparent				7%
Race/Ethnicity of person with ASD				
• Caucasian/European American			74%	
Race/ethnicity of parent/guardian				
• Caucasian/European America				81%
• Latino/Hispanic				10%
Parent/Guardian educational level				
• Less than college				40%
• College degree or more				14%
Total household income before taxes				
• Less than 75,000				57%
• \$75,000 and more				43%

Results in review (the really interesting stuff)

- Parents visited their child's HCP 2-30 times while seeking an ASD diagnosis over a period of 0-10 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 age of ASD diagnosis
 - 2) ethnicity and length of time parents spent seeking a diagnosis

In a highly educated, ethnically diverse sample of respondents living in an area rich in autism resources, parents still struggled to access a diagnosis for their child



3) Focus groups: Parents of children with ASD

Purpose:

- 1) describe parent experiences seeking an ASD diagnosis for their child**
- 2) describe parent responses to receiving the ASD diagnosis**
- 3) describe parent experiences accessing and utilizing ASD services**

Focus groups = 1 focus group

... and turned into individual interviews

Demographic information

... was similar to the survey study

Categories, Themes, Coding

Before Diagnosis	Diagnosis	Seeking Services	Adult Children
Navigating Communication with HCP HCP Knowledge of autism HCP attitude of autism Cookie cutter approach	Diagnosis acceptance Learning and Planning Community awareness Coping Social support Social capital	Wait time and navigating Communication with healthcare providers Knowledge Cookie cutter approach Coverage and consistency Managing and preventing meltdowns Socialization Disability Respite Recreational activities Sensory issues	Transitions Socialization Independence Responsibility Mental health Violence Guardianship

IFSMT Context: Health Care Access

Seeking a Diagnosis

SEEKING A DIAGNOSIS		
Concrete experience	Abstracted	Phenomena
CHILD Resisting closeness Different Not progressing Progressed and then went backwards Focus on objects Navigating Communication with HCP Not feeling heard HCP Knowledge of autism HCP attitude of autism Cookie cutter approach	Hands tied Not knowing Not feeling heard Frustration Disheartened Feeling lost Needing a roadmap	Waiting Uncertainty Not feeling respected Not feeling listened to Hope – no hope Feeling unsure Feeling understood – not understood Restriction – freedom Feeling alone Knowing – not knowing Contentment - disharmony

IFSMT Context: Health Care Access

Diagnosis

DIAGNOSIS		
Concrete experience	Abstracted	Phenomena
Diagnosis acceptance Learning and Planning Community awareness Coping Social support Social capital Lost dreams	Surprise Concerned Disheartened Grateful Not knowing Self-taught Seeing self Overwhelmed	Feeling listened to Uncertainty Knowing-not knowing Feeling unsure Feeling unburdened Feeling understood Joy-sorrow Living with the consequences of personal choices

IFSMT Context: Health Care Access

Seeking Services

SEEKING SERVICES		
Concrete experience	Abstracted	Phenomena
Wait time	Waiting	Waiting
Desperation	Uncertainty	Knowing-not knowing
Disheartened	Frustration	Taking life day-by day
Anxiety	Anxiety	Doing the right thing
Depression	Not knowing	Feeling cared for
Uncertainty	Hands tied	Feeling understood – not understood
Managing and preventing meltdowns	Feeling alone	Feeling close
Childs motivation	Needing a mentor	Hope – no hope
Navigating	Needing a roadmap	Feeling unsure
Communication with healthcare providers	Seeking solutions	Feeling respected – not respected
Lack of knowledge	Seeking services	Feeling unburdened
Seeking knowledge	Not feeling heard	Joy-sorrow
Cookie cutter approach	Not feeling respected	Feeling listened to – not listened to
Disrespect	Making it work	Feeling loved – not loved
Coverage and consistency	Going the distance	Feeling peaceful
Coordination of services	Seeking support	Living with the consequences of personal choices
Diagnosis was the gateway	Learning	Restriction - freedom
Grateful	Sharing	Certainty - Uncertainty
	Lost opportunities	Feeling alone – not alone
	Advocate	Laughing

Unexpected Finding

IFSMT Context: Condition-Specific Factors

Adult Children

- Transitions
- Socialization
- Independence
- Responsibility
- Mental health
- Violence
- Guardianship

Implications

HCP –

- Work with parents
- Knowledge of ASD
- Communicate with parents and child
- Offer support and support referrals
- Facilitate entry into interventional services
- Advocacy
- Develop ASD educational opportunities for HCP

Next steps

- Film
- Road show
 - Knowledge and attitudes
 - Policy and budgetary changes

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