

# ASD Treatment Decision-Making:

## An Exploratory Study on the Decision-Making Process Experienced by Parents of Children with an ASD

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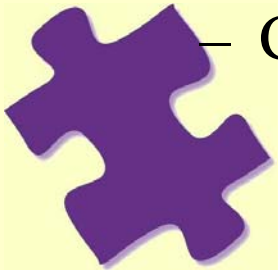
# Why ASD?

- Extended School Year Counselor for Children with ASD
- Honors in Social Work, Developmental Disabilities
- Intern at an Agency Serving Families of Children with Developmental Disabilities



# Autism Spectrum Disorder (A.S.D.)

- Centers for Disease Control and Prevention (2007)
  - Definition:
    - Chronic Developmental Disability
    - Impairments in social interaction and communication
    - Unusual behaviors, interests, and ways of learning
    - Learning abilities vary from gifted to severely challenged
  - 1 in 150 8-year-old children in the US has an ASD
  - Unaware of Cause
  - Currently No Cure, Treat Symptoms



# Introduction

- Treat Individual Symptoms
  - Creates numerous treatment decisions for parents
- Spectrum Disorder
  - Pressure to find treatment appropriate for individual child



# Literature Review

- Midence & O'Neil (1999): Parents Experience during ASD Diagnosis
  - Struggle to Receive Diagnosis
  - Initial Period of Doubt



# Literature Review

- Smith, Chung, & Vostanis (1994):  
Experience of Parents Post Diagnosis
  - Need Information and Support to Relieve Stress



# Literature Review

- O'Rourke (2007): Prostate Cancer Patients
  - “Crash Course” in Illness Characteristics
  - “Crash Course” in Treatment Options



# Literature Review

- Lowes, Gregory & Lyne (2005): Parents of Children with Diabetes
  - Theory of Psychosocial Transition
  - Support during “Stressor Event”
  - Must Accept New Responsibilities





# Literature Review

- Fraenkel & McGraw (2007): Nutrition-Related Decisions of Pregnant Women
  - Risk and Benefit Analysis
  - Requires Extensive Knowledge of Treatment Options



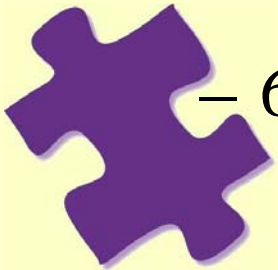
# Literature Review

- Grobe, Manroe & Still (2007): Medical-Decision Making
  - Social Context of Decisions
  - Individual or Guardian Remain Primary Decision-Maker



# Methodology

- Sample:
  - Parents of child
    - Child under 18
    - Child Previously Diagnosed with an ASD
  - Recruitment through Area Agency
  - 9 Parents Interviewed
    - 7 Families Represented
    - 1 Parent Withdrew
  - 6 Families Transcribed & Analyzed



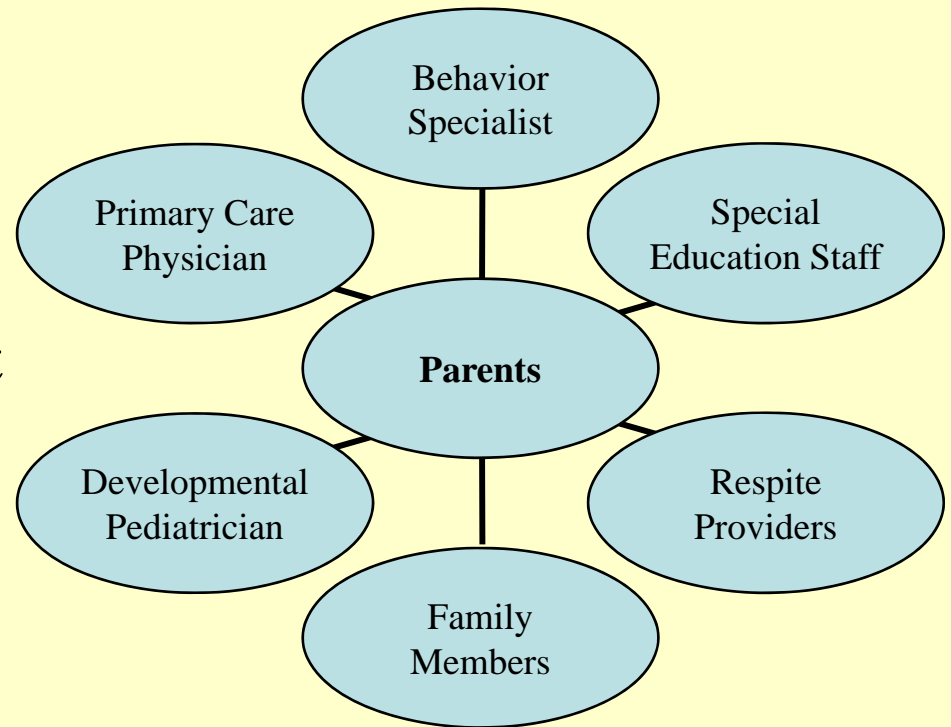
# Methodology

- Data Collection and Analysis:
  - Fink (2006) Interview Conduction Principles
  - 30-45 Minute Interviews
  - Audiotaped
  - One Interviewer/Transcriber
  - Grounded Theory Analysis (Patten, 1987)



# Findings

- System Structure
  - Parents as Central Figures
  - **“They give you the information and let you deal with it.”**  
(Interview 1)



# Findings

- System Structure (cont'd)
  - Pressure to Make Educated Decisions
    - **“It is difficult to be the parent, the doctor, the teacher and the therapist, but parents of kids with Autism learn to do it really fast. They have to.”** (Interview 2)
  - Frustration with System
    - **“I wish there was someone who could say do this, do this, and it is going to make a giant difference and there is nobody who does that.”** (Interview 6)



# Findings

- System of Support
  - Professional and Interpersonal Assistance
    - **“You need a lot of support.”** (Interview 4)
  - Area Developmental Disability Agency
    - **“They all seem to go out of their way to make sure they can direct you where you need to go and they have been really good with us as far as helping make decisions about stuff.”** (Interview 4)



# Findings

- System of Support (cont'd)
  - Educational Support
    - **“You can’t find everything, so you know, we said we’d just share.”** (Interview 1).
  - Finding Information
    - **“There is a great support system out there for most people if they know how to ask.”** (Interview 4)





# Findings

- Determination of Treatment Effectiveness
  - 50% Utilize Trial and Error
    - **“Just trial and error. I mean I would try it and if he wasn’t responding, you know, within a reasonable time just move onto the next thing or add something else.”** (Interview 1).
  - 2/3 Utilize Behavioral Outcomes
  - Trial Periods vary
    - **1-2 Days** (Interview 4)
    - **Long-term** (Interview 6)



# Findings

- Delay in Obtaining a Diagnosis
  - 5/6 Families Experienced Delay
    - **“It took almost a whole year to get him evaluated.”**  
(Interview 1)
  - 1/3 Families Doubted Diagnosis
    - **“We started doing research and saw what the diagnosis actually meant to have Autism, and it wasn’t a Rain Man kind of thing. We were angry at ourselves. When we looked at descriptions we said, “Of course he has Autism. If we had only known this six months ago there wouldn’t be any questions in our mind.”** (Interview 5)



# Discussion

- Practice Implications
  - Provide Social Support Network (Grobe, Manore & Still, 2007)
    - Friends, Family, Support Groups, Chat Rooms, Seminars
  - Provide Educational Support (Smith, Chung, & Volstanis, 1994)
    - Advocacy Training
    - Treatment Options
    - Appropriate Trial Periods
  - Evaluate Delay to Secure a Diagnosis (Midence & O'Neill, 1999)
    - Support During Delay
    - Additional Diagnosis Resources



# Discussion

- Limitations
  - Convenience Sample
  - Not Generalized to Population
    - Small Sample Size
    - Small Geographic Area
  - Recruitment Creates Bias Toward Area  
Developmental Disability Agency



# Discussion

- Future Research
  - Reexamine Decision-Making Process
    - Larger Sample Size
    - Larger Geographic Area
  - Examine Services of Local Agency
  - Determine Need of Delay in Diagnosis



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