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Overview

- Very briefly look at characteristics of ASD
- Briefly discuss the design of the study
- Discuss the results of the study
- Discuss implications of the results
- Questions
Learning Outcomes

- Identify possible areas of misunderstanding between parents and professionals
- Identify the core characteristic of autism most likely to represent differences in behavior seen by parents and teachers
- Identify attitudes and behaviors most likely to lead to collaborative working relationships between parents and professionals
Core Characteristics of ASD

Communication

Social Skills

Behavior
Constellation of Core Characteristics of ASD

Communication

Social Skills

Behavior
Constellation of Core Characteristics of ASD

Communication

Social Skills

Behavior
Demographic Information

- Between 1966 and 1993, 1 in 770 children (Fombonne, 2005)
- Now 1 in 110 children nationwide and 1 in 94 children in New Jersey are diagnosed with ASD (CDC, 2009; CDC, 2007)
- As of the 2003-2004 school year 300,000 children aged 4-17 had been diagnosed with ASD (CDC, 2006)
Possible Reasons for the Dramatic Increase in Cases of Autism

- Improved diagnosis
- Improved recognition of disorder
- Maybe some diagnostic substitution
- Familial links to other psychiatric disorders
- Age of parent
The complex nature of ASD makes designing treatment and education programs that work for each child very difficult (Heflin & Simpson 1998; Shattuck & Grosse, 2007; Simpson, 2005, 2008).

Parents and teachers often disagree about appropriate programs and goals for these children (Heflin & Simpson, 1998; Yell, Katsiyannis, Drasgrow, & Herbst, 2003).
Ideally adults working together to improve educational outcomes of students with ASD will form effective communities of practice. Communities of practice share and create a common interest, expertise, competence, learning, activities, information, experiences, and knowledge (Cousin & Deepwell, 2005; Seaman, 2008; Wenger, n.d., What are communities of practice?).
Methodology

- Qualitative
  - Exploratory, small sample size, unknown variables, understand not explain

- Phenomenological
  - Describe phenomenon, multiple perspectives, use of in-depth interviews

- Three steps
  - Phenomenological reduction, detailed description, search for underlying meaning through imaginative variation (Giorgi, 1997, Philosophical Method, para. 1)
Students Represented

- Gender: Three girls and seven boys
- Age: 6 years 4 months to 16 years 3 months, average age 11 years 6 months
- Race: Six White, two Black, one Hispanic, and one Asian
- Degree of ASD: Two mild, three moderate, and five severe ASD
Research Population

- Mothers
  - Age: 30 to 57, average age 41
  - Race: Six White, two Black, one Hispanic, and one Asian
  - Experience with ASD: None other than experience with child
Research Population

- Teachers
  - Gender: Two men and five women
  - Age: 23 to 44, average of 36
  - Race: Six White and one Black
  - Experience with ASD: 6 months to 5 years, average 21 months
Data Collection

- All participants were interviewed using the same semi-structured interview format.
- Open-ended follow-up questions and probes were asked as needed to clarify responses and achieve a deep understanding of the participants’ perspectives (Salkind, 2003).
Data Collection

- Recording the interviews on audio tape increased the reliability of the data collection (Tuckett, 2005).
- Notes were taken regarding affect, attitude, and nonverbal communication during the interviews.
Data Analysis

The results were analyzed according to the process adapted by Giorgi (1997, 2008) from Hycner’s (1985) approach

- Transcribed word for word
- Units of meaning delineated
- Units of relevant meaning described
- Clusters of meaning developed
Data Analysis

- Units of relevant meaning and clusters of meaning for parents and teachers compared
Data Analysis

- Comparisons analyzed
- Results compared with student records
General Results

- Mothers were lonely, depressed, and frustrated
- Mothers anxious regarding their children’s communication, the difficulty their children will have in participating in post secondary school life, and what would happen to the children if anything happens to the mothers.
General Results

- Mothers appeared relieved to have a listener and gave an intimate picture of life with a child with ASD.
- Mothers used more descriptive less clinical language than teachers.
- The teachers remained calm during their interviews whereas all of the mothers cried at least once.
Comparison of Parent-teacher Units of Relevant Meaning

- Mothers and teachers do not describe the communication, social skills, and behavior of children with ASD using the same words.
- The subtle differences in words used may cause misunderstandings and miscommunications to arise.
- Changes in a child noticed and other issues mentioned were different for mothers and teachers.
Comparison of Parent-teacher Clusters of Meaning

- Disagreements about skills arose in only 15 out of 412 items in the clusters of meaning.
- Twice as many items in the cluster of behavior than in any other cluster for both parents and teachers.
Comparison of Parent-teacher Clusters of Meaning

- Elementary students had more instances of similarity and fewer instances of disagreement than students in the middle and high school classes.

- Higher functioning students had fewer instances of similarity and more instances of disagreement than students in the lower functioning classes.
Comparison of Parent-teacher Clusters of Meaning

Clusters for communication and social skills revealed more similarities (36 similar concepts) than differences (9 disagreements). The parents and teachers of the younger more severe students had no disagreements regarding the children’s behavior.
For the three older higher functioning students, the teachers described their behavior more positively than the parents did because of a difference between the behavior experienced at school and at home.
Comparison of Parent-teacher Clusters of Meaning

- The number of concepts used by teachers in the cluster of changes since the child has been with the current program was higher than for parents.
Comparison with School Records

- For all students information resulting from the parent and teacher interviews agreed with information found in the Present Levels of Educational Performance section of the students’ current Individual Education Plans (IEP).

- School records confirmed the severity of ASD for all students.
So What?

- Parents are not the enemy
- Unless we are parents of a child with autism we cannot possibly understand what they are going through
- Understand that parents and schools personnel may see different communication, social skills, and behavior
And

- Understand that the subtle differences in descriptions found in this research mean that parents and teachers need to work to understand each other’s perspectives in order to form effective collaborative relationships.
And

- Parental and professional concerns need to be discussed openly so that everyone can agree to work toward the same goals and all outcomes can be considered (Russell, 2005).
So

- Understanding and open communication will empower families to work with professionals for the benefit of their children (Howland et al., 2006).
Collaborative relationships will improve the effectiveness of the education of children with ASD and may lead to the early resolution of conflicts and the prevention of expensive due process hearings and litigation (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).
What can we do?

- Understand familial stressors related to raising a child with ASD (McWayne, Hampton, Fantuzzo, Cohen, & Sekino, 2004)

- Listen to the families’ concerns and goals for their children (Howland, Anderson, Smiley, & Abbott, 2006; Lake & Billingsley, 2000).
What can we do?

- Understand that parents are knowledgeable experts with regard to their children (Forlin & Hopewell, 2006; Murray et al., 2008).

- Develop shared expectations for behavior in order to reduce the stress experienced by parents and teachers as a result of children’s violent and defiant behavior (Lecavalier et al., 2006).
How do we do this?

- Have realistic expectations for family involvement
- Be nonjudgmental
- Provide parents with information regarding agencies and programs that provide services for families of children with special needs
How else can we help?

- Provide the parents with realistic information that is easy for them to handle
- Provide parents with information about common difficulties that families experience with their children with autism
- Provide parents with safe opportunities to meet together for information and family fun
And

- Avoid using words that may shut the parent down (severe, profound, bad)
- Use every day language rather than professional jargon
- Make sure that we understand exactly what the parent means
And

- As difficult as these children are to work with there are many positive things we can say about them. The parents need to hear these.
Final Thought

“You know what, didn't you know that we think that no other child or anybody exists except ours and you should know that. That's what I'm telling you. I feel sorry because I do kind of figure that maybe the specialists and the teachers sometimes and we're like you know we're thinking that our child is the world that's it you know. You'd better know h_, you'd better have time for h_ we really think that honestly we do. We really think that way. You'd better call me back right away. I mean there is a lot of... I do feel sorry when I think about that, because as a parent I'm sure that that's kind of stressful on their end. I'm thinking they didn't call back yesterday. We're not thinking you have a ton of people, we're thinking we're it you know. That's how we feel all the time.”
Questions


References Continued


References Continued


References Continued


Autism Spectrum Disorders

- Autism
- Asperger’s Disorder
- Pervasive Developmental Disorder not Otherwise Specified (PDD-NOS).
- Rare, Rett’s Syndrome (girls only)
- Childhood Disintegrative Disorder (loss of skills after at least two years of normal development)
Demographic Information

- For diagnosis symptoms must appear before age 3
- Between 1966 and 1993, 1 in 770 children (Fombonne, 2005)
- Now 1 in 110 children nationwide and 1 in 94 children in New Jersey are diagnosed with ASD (CDC, 2009; CDC, 2007)
- The ratio of boys to girls with ASD is 4.5:1 (higher in high functioning autism and Asperger’s, girls tend to be more severe) (CDC, 2009)
Demographic Information

- 41 to 70% of children with ASD have some cognitive impairment (CDC, 2009; Taylor, 2006)
- 40% of children with ASD have severe verbal communication problems (Richard, 1997)
- 20 to 40% of children with ASD developed normally until about age 2 and then regress (Taylor, 2006)
Demographic Information

- Latest research is beginning to indicate that up to 10% may improve to the point that they are indistinguishable from neurotypical peers.
- As of the 2003-2004 school year 300,000 children aged 4-17 had been diagnosed with ASD (CDC, 2006)
Additional Issues in Autism

Child can have other problems as well as ASD:
- Learning disabilities
- ADD/ADHD
- OCD
- ODD
- Speech problems
- Manic Depression/Depression
- Seizure Disorder
- Digestive Disorders
Causes of Autism

- Genetic link (multiple genes involved)
- Environmental triggers
- **NOT** MMR vaccine or mercury in vaccinations
  (Rutter, 2005)
Background

- The reauthorization of IDEA in 1997 mandated parental involvement in all aspects of the education of children with special needs (Stoner et al., 2005).
- The complex nature of ASD makes designing treatment and education programs that work for each child very difficult (Heflin & Simpson 1998; Shattuck & Grosse, 2007; Simpson, 2005, 2008).
- Parents and teachers often disagree about appropriate programs and goals for these children (Heflin & Simpson, 1998; Yell, Katsiyannis, Drasgrow, & Herbst, 2003).
- Disagreements can result in litigation, which has increased parallel to the increase in the number of children diagnosed with ASD (Yell et al., 2003).
Problem

The problem is that although the number of parents and teachers who are called on to agree about the assessment and services to be provided to children with ASD has increased dramatically, little is known about the actual similarities and differences in perceptions held by parents and teachers who are working with the same children.
The purpose of this study was to explore the similarities and differences in the descriptions of the communication, social, and behavior characteristics of elementary, middle, and high school children with ASD made by parents and teachers.
Research Question

What are the similarities and differences in the descriptions by parents and teachers of the communication, social, and behavioral characteristics of children with ASD who are enrolled in ASD classes in an educational service agency in New Jersey?
Todd is very... he is very verbal. He's not afraid to talk to you. He's very inquisitive.

He asks a lot of questions. I notice that he asks a lot of the same questions over and over again even though he knows the answers to them. Like he'll ask "where's (former aide)?" or "Is (former aide) not here because she doesn't like us?" "Is that why she left because she doesn't like me?" and he knows that she is over at (another school). ....

A. ...he is very verbal  
B. He's not afraid to talk to you. 
C. He's very inquisitive. 
D. He asks a lot of questions. 
E. ...he asks a lot of the same questions over and over again even though he knows the answers to them. 
F. (topics) Dogs, cats, cows. 
G. he only has two or three questions that he ever asks.

A. Very verbal  
B. Has topics of interest (animals)  
C. Asks questions over and over again (only has two or three questions that he asks) even when he knows the answer  
D. Very inquisitive  
E. Not afraid to talk to you
A Comparison of the Number of Concepts used by Parents and Teachers in each Cluster of Meaning

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<th>Group</th>
<th>Communication</th>
<th>Social Skills</th>
<th>Behavior</th>
<th>Changes in Child</th>
<th>Difference of Opinion</th>
<th>Other Issues</th>
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Confirming Comparison to Literature

Literature
- Parents and teachers do not necessarily agree on the nature and severity of behavior problems but both parents and teachers associate behavior problems with stress (Lecavalier, Leone, & Wiltz, 2006).

Whittinghill’s Results
- Parents and teachers used twice as many items in behavior cluster than in any other indicating that behavior is a critical issue for both parents and teachers.
Confirming Comparison to Literature

Literature
- Parents place a statistically significant degree of importance on issues of safety, adult responsibility, and success in education (Ivey, 2004).

Whittinghill’s Results
- All but two of the parents who mentioned concerns had concerns about their child’s future life and or safety.
Experienced teachers were more comfortable communicating with parents because they know more about the community and the characteristics of the students (Melnick & Meister, 2008).

None of the three new teachers mentioned any other concerns or issues indicating perhaps that they were not aware of how important these issues may be for parents.
Confirming Comparison to Literature

**Literature**
- Parents report at least one negative experience with their child’s education (Anderson, Meyer, & Somers 2006; Bennett, Hwa, & Lueke, 1998; Duncan, 2003; Fish, 2006; Hess, Molina, & Kozleski, 2006; Stoner & Angell, 2006).

**Whittinghill’s Results**
- Five of the parents in this study reported differences of opinion with their child’s previous school.
Confirming Comparison to Literature Continued

Literature

- 90% of their participants identified different perceptions of a child or a child’s needs as a major factor in the conflict they had experienced with schools (Lake & Billingsley, 2000).

Whittinghill’s Results

- Three of the five mothers who reported disagreements with their children’s previous schools reported that these disagreements were the result of the school failing to understand their child and not listening to the parents’ concerns.
Confirming Comparison to Literature Continued

**Literature**
- 90% of the parents of children in special schools and 60% of the parents of mainstreamed children were satisfied with their child’s education (Whitaker, 2007).

**Whittinghill’s Results**
- All of the parents were happy with their child’s current school placement.
Children might not display the same behaviors at school and at home (Szatmari, Archer, Fisman, & Streiner, 1994; Murray et al., 2009).

4 out of 10 interview pairings the mothers described very different behavior in the home than the teachers described in the school.
Disconfirming Comparison to Literature

**Literature**

- Parents have more positive ideas about their child’s social skills than teachers do (Murray, Ruble, Willis, & Molloy, 2009).

**Whittinghill’s Results**

- In the clusters of meaning for communication and social skills, this research revealed more similarities than difference in the parents’ and teachers’ descriptions.
Disconfirming Comparison to Literature

- **Literature**
  - 90% of the respondents identified different descriptions of a child or different assessment of a child’s needs as the major factor in conflict (Lake & Billingsley, 2000).

- **Whittinghill’s Results**
  - Actual disagreements about the child’s skills arose in only 15 out of 412 (4%) items in the clusters of meaning.
Disconfirming Comparison to Literature

Literature

- Parental perception and professional assessment regarding the child’s cognitive level are significantly different with the parental estimate being higher and greater agreement for higher functioning students than for lower functioning students (Geiger, Smith, & Creaghead, 2002).

Whittinghill’s Results

- During this research, no attempt was made to discuss the parent and teacher perception of the child’s cognitive level. This research found a greater similarity of description with lower functioning students than with higher functioning students.
Suggestions for Future Research

- Quantitative study with larger sample size
- Consistency of behavior across settings between higher and lower functioning children
- Age of the student and the severity of ASD and the number and degree of concerns held by parents and teachers in a variety of life areas
- Similarity and differences in the way that parents and teachers view the core characteristics of the children if they are asked to make judgments regarding the severity of the child’s skills.
Suggestions for Future Research

- Difference in perceptions of older more experienced teachers and younger less experienced teachers and whether level of experience with ASD of a teacher influences the number of differences of opinion between the parents and the teachers.
- Effect of parent and teacher training on the quality of collaborative relationships and the number of disagreements or conflicts that arise.
- Father’s perceptions