

What Do Parents Expect?

A Study of Likelihood and Importance Issues for Children with Autism Spectrum Disorders

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The purpose of this study was to investigate the expectations of parents of children with autism with regard to importance and likelihood issues of future outcomes. Participants in the study were 25 parents in two midwestern states. Each set of parents had a child diagnosed within the autism spectrum. Results indicated that parents perceived a higher degree of importance than likelihood for future outcomes. Parents expressed extreme concerns about their child's protection and safety. In addition, there were statistically significant differences between importance and likelihood for issues of safety, adult responsibility, and success in education, with importance rated higher than likelihood.

Because today increasingly more children are being diagnosed with autism (Hardman, Drew, & Egan, 1999; Huebner, 2001; Lord & Risi, 2000), there are increased educational concerns about outcomes and quality of life. Parental expectations determine many aspects of a child's education; therefore, it is important to examine parent expectations for children with autism.

For several decades, children with autism have not been understood. This has led to misdiagnoses, experimental treatments, and frustrated parents. The growing concerns for children with autism are numerous. Parents are struggling with educational choices, such as continuum of services, related services, educational settings, and interventions. These challenges that parents experience are due to the increased number of diagnoses of the disability and the controversial philosophies regarding treatment. Autism is a low-incidence disability, in that it occurs in approximately 1 to 2 individuals per 1,000.

Theoretical Framework

Parents were the pioneers in starting special education programs in the school systems. It is critical that family members be seen as essential members of the educational process (Fox & Williams, 1992). Although parents are expected to play a supporting role in the schools' efforts, many times they receive little support themselves and are expected to provide little input. Research indicates that fam-

ily systems must be acknowledged as valuable (Gray, 1998; Simpson, 1990).

Literature on the expectations of parents of children with disabilities has found correlational evidence linking parents' expectations and involvement with future outcomes that children with disabilities achieve. For instance, Field and Hoffman (1999) presented the important link between family involvement and a child's self-determination. Turnbull and Turnbull (1996) identified four components of families that affect self-determination (thus affecting outcomes): family characteristics, family interactions, family functions, and family lifespan issues. Similarly, Kohler (1999) surveyed 25 families of children with pervasive developmental disabilities regarding services they received. The findings showed that parents believed that because they were the primary contact in their children's lives, their opinions and expectations should have more importance than the judgments or opinions of school personnel. In a similar study, Mutua (2001) discussed the importance of parents' beliefs about and expectations of their children with severe disabilities.

Much research has been conducted on expectations and outcomes. Researchers have found that expectations are often positively related to future outcomes for children (Field & Hoffman, 1999; Mutua, 2001). Expectancy theory is an approach to better understanding a person's expectations of specific outcomes, and the values a person places on those outcomes (Bandura, 1995). Individuals perform because of their expectations and act on their beliefs about the probable outcomes of performance. Outcome expectancies are a form of cognitive motivation.

Though outcome expectancy and efficacy expectation are related, they are separate concepts. Outcome expectancy involves a person's belief that certain behaviors will lead to certain outcomes; efficacy expectations hold that one can behave in such a manner as to produce the outcomes (Bandura, 1977, 1992). A person can understand the likely consequences of some action but not be able to execute the action.

Expectancy theory recognizes that an individual's motivation and influence on expectancies are driven by self-efficacy. People often do not pursue a particular

service or treatment because they lack self-confidence. These motives are often related to past abilities or prior task performance (Feather, 1982).

Expectancy theory is enhanced when self-efficacy is included in the formula (Ajzen & Madden, 1986; DeVries, Dijkstra, & Kuhlman, 1988; Schwarzer, 1992). Individuals do not feel that services or treatment options in areas of low perceived self-efficacy are worth taking into account. This is true no matter what their beliefs about a treatment philosophy or service. Self-efficacy beliefs hinder our expectations and influence decision-making. Additionally, the stronger an individual's self-efficacy in fulfilling educational requirements, the more likely it is that they will pursue different service and treatment options in education (Betz & Hackert, 1981; Matsui, Ikeda, & Ohnishi, 1989). In the present study, expectancy theory was used as a basis for examining parental expectations regarding outcomes for children with autism.

Research dealing with families of children with autism is scant. Given that the diagnosis of autism is on the rise (Fleming, 1999), it is therefore necessary to have more information about different aspects related to future outcomes of children with autism. The research question that guided this study was, To what extent do parents' expectations differ on their ratings of the likelihood and importance of achieving specific outcomes of children with autism?

Method and Procedure

Participants

Participants for this study were drawn from a population consisting of parents of children with autism in two midwestern states. Through convenience sampling, a total of 25 parents were surveyed. One father, 21 mothers, and 1 aunt opted to participate in this study. In two cases the mother and father completed the survey together. The return rate was 46%.

Responding to this study were parents in a national parent support group, as

well as parents whose children were enrolled in public school settings. The children from these two groups of parents had been diagnosed with developmental disabilities (e.g., mild to severe autism, Asperger syndrome, Rett's syndrome, pervasive developmental disabilities).

Parent Demographics. Of the 25 parent participants, 24 had enrolled their child in public school settings. None had enrolled their child in a private school setting; however, one parent reported enrolling the child in both public and private schools. Nineteen parents reported that the child with autism had one or two siblings and two parents reported that the child has three or more siblings in the household. Four of the parents had no other children. The majority of the parents were Caucasian (17); 4 parents were African American, 3 were Hispanic, and 1 was Asian American. Seventeen parents resided in urban settings, four lived in suburban settings, and three lived in rural areas.

Classroom involvement was varied among the parents. Thirteen of the parent participants reported contact on a daily basis, six on a weekly basis and one on a monthly basis. Classroom contact once a year was indicated by two of the parents, and no contact was reported by three parents. Of the 25 children targeted, ages ranged from 4 through 20 years, with the majority of parents having children from age 6 to age 10.

Child Demographics. Diagnoses indicated eight children with mild autism, six with moderate autism, and six with severe autism, for a total of 80%. Asperger syndrome was reported in four of the children, and Rett's syndrome was reported only in 1, making up the final 20% of diagnoses. Of the 25 children who were targeted, 32% had additional diagnosed disabilities.

Instrument

The 20-statement instrument that was used in this study was adapted from Mutua (1999) with the purpose of collecting data about teachers' and parents'

expectations of future outcomes for their children with autism. An expectation involves preparing for or envisioning an outcome (Mish, 1988). The term *outcome* is used to describe a future achievement for a child (Ruble & Dalrymple, 1996).

Parents were asked to rate how important it was to them that their child achieve the future outcome specified by each item derived from theory on autism. The responses were scored on a 5-point scale (1 = *highly unimportant*, 5 = *very important*). Likewise, with regard to likelihood of expectations, responses were scored on the same scale, a 5-point Likert-type scale ranging from *highly unlikely* (1) to *very likely* (5).

Evidence of Reliability. Because the survey used a Likert-type scale, Cronbach's alpha was used to assess internal consistency. The data were determined to have a reliability coefficient of .90 for Importance of Expectations and .93 for Likelihood of Expectations. The reliability coefficient for the data as a whole was .91. These high alpha values indicate that the instrument and its parts measure the same characteristics. This is consistent with the reliabilities for importance and likelihood (.90 and .93, respectively) reported by Mutua (1999).

Evidence of Validity. Validity of the data must be evaluated within the context of the purpose of the study. Because it is important in this study that the measures fit the theories for which the survey was designed, construct validity should be discussed. Although construct validity cannot definitively be established, several kinds of evidence were established for the survey upon which the survey in this study was based.

With respect to construct validity, this instrument was considered to be valid for this particular study, as it was used in the recent past to investigate expectations for children with disabilities, including autism. The items included in this instrument were developed from constructs that have been shown through research to relate to future outcomes for children with

disabilities (Mutua, 1999). In addition, Mutua used exploratory factor analysis to study the nature of the theoretical factors on a survey that explored expectations of parents. She found that the survey was composed of four factors with a high correlation and content equivalency across ratings of importance and likelihood. Those four factors were adult roles, importance of community and civil access, importance of educational attainment, and importance of personal fulfillment. These constructs fit the theory for which the survey was designed.

Data Analysis

Parents' ratings of the likelihood and importance of achieving particular outcomes for children with autism are the focus of this study. In addition to statistical tests, confidence intervals are reported. The relationship between likelihood and importance of outcome issues for parents was examined. A paired *t* test was used to determine if the differences between the two constructs significantly differed from

zero. The 95% confidence interval was calculated for each comparison. This allowed the examination of the degree of variability in the corresponding population from which the sample was drawn. If the interval did not include zero, the results were considered to be significant. The data were examined for likelihood and importance differences as whole constructs and on an item-by-item level.

Results

The research question explored the extent that parents' expectations differed on their ratings of the likelihood and importance of achieving specific outcomes for children with autism. The means and standard deviations for all responses are given in Table 1.

A paired *t* test was used to determine if the differences between the two constructs significantly differed from zero. The 95% confidence interval was calculated for each comparison. If the interval did not include zero, the results were

considered to be statistically significant (Huck & Cormier, 1996). The results of the *t* test are shown in Table 2.

The data were examined for likelihood and importance differences as whole constructs and on an item-by-item level. The difference between the means of the total importance and total likelihood responses was significant at the .01 level. That indicates that the parents differed significantly in their assignment of importance to, and expectations of achieving, particular outcomes for their children.

There were five differences between importance and likelihood that were statistically significant at the .01 level. For "support network of friends," "secure financial future," "safe from physical harm," "highest education possible," and "have own children," the means for importance were higher than the means for likelihood. However, except for "have own children," the standard deviations were higher for likelihood. This indicates a wider range of responses for likelihood than there were for importance.

TABLE 1
Means and Standard Deviations of Parents' Expectations

My child with autism will . . .	Importance				Likelihood			
	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
1. . . . be happy and satisfied.	4.72	.54	3.0	5.0	4.16	.99	1.0	5.0
2. . . . attend school.	4.96	.20	4.0	5.0	4.84	.37	4.0	5.0
3. . . . get married.	3.38	1.40	1.0	5.0	2.92	1.35	1.0	5.0
4. . . . own a house.	3.56	1.26	1.0	5.0	3.16	1.25	1.0	5.0
5. . . . support network of friends.	4.68	.56	3.0	5.0	3.80	1.19	1.0	5.0
6. . . . practice religion of choice.	3.92	1.19	1.0	5.0	3.72	1.43	1.0	5.0
7. . . . be accepted in the community.	4.56	.65	3.0	5.0	4.04	.79	2.0	5.0
8. . . . have a secure financial future.	4.68	.48	4.0	5.0	4.04	.93	1.0	5.0
9. . . . be safe from physical harm.	4.92	.28	4.0	5.0	3.84	.90	2.0	5.0
10. . . . attain highest education possible.	4.68	.75	2.0	5.0	3.92	.95	2.0	5.0
11. . . . help with household chores.	4.44	.77	2.0	5.0	4.28	.84	1.0	5.0
12. . . . be socially responsible/law abiding.	4.64	.49	4.0	5.0	4.16	.90	1.0	5.0
13. . . . take care of parent in old age.	1.58	.78	1.0	4.0	1.96	1.12	1.0	5.0
14. . . . participate in citizenship activities.	3.44	1.12	1.0	5.0	3.04	1.10	1.0	5.0
15. . . . live independently.	4.40	.65	3.0	5.0	3.36	1.19	1.0	5.0
16. . . . have time to play/watch games.	4.40	.71	3.0	5.0	4.28	.74	3.0	5.0
17. . . . hold a job/vocation.	4.64	.57	3.0	5.0	3.92	1.00	1.0	5.0
18. . . . have own children.	2.96	1.59	1.0	5.0	2.76	1.48	1.0	5.0
19. . . . use community services.	4.24	.72	3.0	5.0	3.92	.86	2.0	5.0
20. . . . be successful in school.	4.60	.71	3.0	5.0	3.88	1.20	1.0	5.0
Total	83.17	9.36			73.83	14.12		

TABLE 2
Results of Paired-Sample *t* Test for Importance and Likelihood Responses of Parents

Pair	Mean difference	Std. error of mean difference	95% confidence interval of the difference		<i>t</i>	<i>df</i>	Sig. (2-tailed)
			Lower	Upper			
I1 & L1	.56	.22	.11	1.01	2.59	24	.016*
I2 & L2	.12	6.63	-.02	.26	1.81	24	.083
I3 & L3	.46	.27	-.10	1.02	1.70	23	.102
I4 & L4	.40	.26	-.13	.93	1.55	24	.134
I5 & L5	.88	.26	.34	1.42	3.38	24	.002**
I6 & L6	.20	.23	-.28	.68	.87	24	.395
I7 & L7	.52	.20	.11	.94	2.59	24	.016*
I8 & L8	.64	.21	.21	1.07	3.09	24	.005**
I9 & L9	1.08	.19	.69	1.47	5.66	24	.000**
I10 & L10	.76	.21	.33	1.19	3.61	24	.001**
I11 & L11	.16	.19	-.23	.55	.85	24	.405
I12 & L12	.48	.17	.12	.84	2.75	24	.011*
I13 & L13	-.38	.22	-.84	.09	-1.68	23	.107
I14 & L14	.40	.26	-.33	.93	1.55	24	.134
I15 & L15	1.04	.28	.46	1.62	3.72	24	.001**
I16 & L16	.12	.15	-.18	.42	.83	24	.417
I17 & L17	.72	.22	.27	1.17	3.27	24	.003**
I18 & L18	.20	.24	-.29	.69	.84	24	.409
I19 & L19	.32	.22	-.14	.78	1.45	24	.161
I20 & L20	.72	.24	.22	1.22	2.98	24	.007**
I total & L total	9.33	2.83	3.49	15.18	3.30	23	.003**

Note. I denotes statements concerned with importance, and L denotes statements concerned with likelihood.
* $p < .05$. ** $p < .01$.

Differences in the responses for importance and likelihood for the statements "happy and satisfied," "accepted in the community," and "time to play and watch games," were significant at the .05 level. For all three of these statements the means for the importance responses were higher than the means for the likelihood responses. However, the standard deviations for likelihood were greater than the standard deviations for importance for these statements.

Discussion

The mean of the total responses for importance was 83.17, compared with 73.83 for likelihood. Parents might value a particular outcome but still believe that their child would struggle with attaining it. The total standard deviation for importance was 9.36, compared with 14.12 for likelihood. This may be a result of the broad spectrum of skill levels of the chil-

dren within this study. In addition, the broad array of diagnoses might have contributed to the likelihood responses.

For both importance and likelihood, the lowest means were for "take care of parent in old age"—1.58 and 1.96, respectively. A possible explanation for this is that most of the parents (63%) who responded in this study had children aged 6 to 10 years, and parents of younger children might not believe that a child this young could actually care for them when they are old; therefore, it is not important. In addition, most of the children had siblings (84%), so perhaps the parents believed that those siblings would assume the responsibility of caring for them in their old age. Alternatively, professionals have reiterated and stressed that the child with autism will need to be cared for possibly throughout adulthood, and parents might not feel that role reversal is possible.

For the importance category, the mean was the highest (4.96) for "attend

school." The parents valued education and realized it was important for their child to learn the skills necessary for success in the community. The services and programs available in schools were deemed important by these parents. Moreover, there is a direct connection between parents' expectations and the services they seek for their children (Carnie & Orelove, 1998; Mutua & Dimitrov, in press). In addition, the likelihood mean (4.84) was also highest for "attend school." All of the children in this study were enrolled in a school setting and seemed likely to remain in school. It is interesting to note that the highest and lowest means pertained to the same statements for both importance and likelihood.

There was a statistically significant difference for the total importance and total likelihood responses for parents, $t(23) = 3.30$, $p = .003$. Parents believed that the importance of the outcomes was greater than the likelihood of those outcomes.

According to these results, parents of children with autism may have difficulty maintaining their optimism about a variety of outcomes for their children.

There were seven statements for which the differences between importance responses and likelihood responses were statistically significant at the .01 level: "support network of friends," "secure financial future," "safe from physical harm," "highest education possible," "live independently," "hold a job/vocation," and "be successful in school." The three statements that were statistically significant at the .05 level were "happy and satisfied," "accepted in the community," and "socially responsible/law abiding."

While no significant difference was found between importance and likelihood of their children attending school, there was a statistical significant difference with regard to receiving the highest education possible, as well as to being successful in the school. Apparently, the parents of these children with autism believed that achievement and long-term attendance was questionable. It is possible that many of the parents were not familiar with the curriculum or did not understand the types of interventions carried out in the school systems. Physically being in school appears to be the highest expectation for the parents.

With regard to the importance of their children's being safe from physical harm, parents' responses were extremely high. However, they rated the likelihood of this happening significantly lower. This surprising result could be an indication of the doubts the parents had about their children's ability to protect themselves.

Several of the significant statements dealt with adult responsibilities. Although parents deemed it important that their children be accepted in the community, be financially secure, be socially responsible, live independently, and hold jobs, they did not believe it was likely that this would actually occur. Some reasons for this might be the unique and sometimes disruptive behaviors children with autism may exhibit; in addition, such behaviors and the lack of particular skills can interfere with jobs, earning a living,

and being an active member in the community (Green, 1996).

There was a discrepancy between importance and likelihood for the issues of being happy and satisfied as well as having a supportive network of friends. This indicates that parents desired their children to have personal fulfillment in their lives but did not necessarily expect that they would experience it. The lack of social skills and communication could be at least in part a cause.

Implications

Traditionally, "good outcome" has been defined as having a normal social life and achieving independence (Gillberg & Steffenburg, 1987; McEachin, Smith, & Lovvaas, 1993). If held to these criteria, many children with autism would be considered to have poor outcomes in their lives. Lord and Venter (1992) argued that another important aspect of outcome is happiness. Furthermore, Rosen, Simon, and McKinsey (1995) recommended that quality of life be the guiding framework for programs and services. Ruble and Dalrymple (1996) suggested that a good outcome be expressed in terms of the interaction between a person and his or her environment.

Parents. The results of this study send a strong message about the doubts parents have about the safety of their children with autism. In a series of focus groups, parents of children with disabilities expressed extreme concerns about their children's protection and safety (Davern, 1999). If parents do not feel that their children will be safe, their decisions will be based on that (e.g., keeping the child away from community activities). In addition, parents may be overprotective, thereby limiting independent-type skill development for these children (Powers, 2000). One cannot overlook the influence parents have with on their children, particularly those with special needs. A child's development is critically influenced by judgments that parents make. Parental expectations not only predict children's self-perceptions but also have been shown to predict actual achieve-

ment (Eccles, 1983; Entwisle & Baker, 1983; Phillips, 1987; Reynolds & Gill, 1994).

Educators. It is important that both educators and parents fully understand the nature of autism as well as understand the necessity for collaboration. Significant discrepancies between parents' and educators' expectations could be detrimental to the child. Any incompatible ideas must be comprehended by each group (Stone & Rosenbaum, 1988). If parents and teachers do not agree on the likelihood of future outcomes, chances are they will not have the same long-term goals for the child. For example, a parent might want instruction in the area of daily living skills, whereas the teacher feels that his or her time is better spent working on skills dealing with community involvement. In addition, if parents and teachers have different values about outcomes, conflicts or poor communication between the two may arise.

Clinicians. Professionals in clinical settings need be aware of parents' strong feelings regarding future outcomes, and address their concerns, when communicating with the families. Developing the agenda in working with children with autism should be a collaborative effort between all parties involved. In addition, one must be ready and able to assist families in developing tools for communication with educators and those who will directly influence and facilitate the expected future outcomes.

Future Research

A comparison of the responses of mothers and fathers with regard to future outcomes for their children would be enlightening. This would reveal whether expectations differ between mothers and fathers and if so, how much and in what areas. In addition, a researcher could conduct an analysis to investigate differences in mild, moderate, and severe autism expectations. This would allow one to see what discrepancies exist, if any, on expectation outcomes for these different groups.

Another possible suggestion is to interview parents to investigate why they answered the way they did on this survey. Such qualitative information may help to determine factors of expectations. In addition, it might clarify any bias that occurred when participants tried to separate importance from likelihood.

Because autism is a low-incidence disability, sample size was considered appropriate. However, more information could be obtained with a larger sample, however difficult that might be. Increasing sample size could result in finding statistically significant differences between importance and likelihood outcomes.

Summary

Research indicates that when the influential people in a child's life do not believe that he or she has potential to achieve an outcome, it is unlikely that the outcome will be realized. For example, if a parent and teacher perceive that a child has social difficulties, those perceptions may increase the undesirable behavior and the child may see himself or herself in that light (Donohue, Weinstein, Cowan, & Cowan, 2000).

One cannot ignore quality-of-life issues when conducting this study. Children with autism often have communication, interaction, and behavior difficulties. With these challenges, they may not be able to voice their thoughts and feelings to others. It is critical that parents allow children with autism to make their own choices and express their desires and interests.

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