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AN ALTERNATIVE VIEW OF OUTCOME IN AUTISM

Parents often rely on the knowledge and experience of others to explain the longitudinal outcomes in autism. Unfortunately, limitations keep parents from obtaining accurate and relevant information. First, professionals with limited experiences are not likely to understand the range of outcomes for persons with autism. Second, previous studies have used narrow explanations to define outcomes. Past researchers have generally defined good outcome as the development of a normal social life and independence by adulthood; and they have defined the best predictors as verbal and IQ levels. Because most individuals with autism continue to struggle with social relationships and need individualized supports, this outcome is rare. Parents, educators, and researchers need other frameworks now to characterize and conceptualize "good outcome." Data on 46 individuals with autism will be used to present an alternative view of outcome. Some who would have been predicted to do poorly as adults because of their relatively low verbal, cognitive, and adaptive behavior levels were found to be leading satisfactory lives. To illustrate the multitude of variables that have an impact on outcome and to propose the claim that competency and quality of life are the best criteria for judging outcomes, we present four case studies.

Soon after a child is diagnosed with autism, parents want to know what their child can learn and accomplish in the future. They often ask if their child will outgrow the autism, live independently, graduate from school, have a job, go to college, have friends, be a happy person, and live a productive and fulfilling life. Parents want to know what the quality of life will be for their child with autism and express concern that service providers be able to understand their perspective.

To get the answers to their questions, many parents rely on the knowledge of educational and medical professionals. However, at least two limitations are likely to keep parents from obtaining accurate and relevant information. First, a survey by Stone (1987) suggests that professionals with limited experience are not likely to have up-to-date information about autism or an understanding of longitudinal outcomes. For example, many were not sure whether autism occurred only in childhood and whether with proper treatment children would outgrow autism.

A second limitation concerns the definitions of outcome used in past research studies. Most researchers of longitudinal studies described a dismal picture of the future. Professionals who communicate these definitions to parents are more likely to present narrow possibilities that do not reflect the current situation for people with autism. With the changes in service delivery that are based on recently articulated social values of encouraging community living with supports, people with autism are being provided more options than ever before. Quality of life is now likely to be the guiding framework for developing programs and providing services, including an emphasis on the evaluation of environments (Rosen, Simon, & McKinsey, 1995). However, the measurement of quality of life for people with autism has yet to be investigated.

This discussion of two views of outcome is meant to accomplish one purpose: to urge professionals to pause and rethink the crystal ball. In this review of 46 individuals with autism, no clear picture emerged for any individual. However, it became apparent from the case study descriptions that many factors other than IQ were critical to outcome--that is, if outcome is reconceptualized.

Traditional Definitions of Outcome

Although longitudinal studies of autism are difficult to compare to one another (Freeman, Ritvo, Needleman, & Yokota, 1985; Wolf & Goldberg, 1986), researchers have generally defined outcome similarly. A "good outcome" was the achievement of independence and the development of a normal social life (DeMyer et al., 1973; Gillberg & Steffenburg, 1987; Kobayashi, Murata, & Yoshinaga, 1992; Lotter, 1978; McEachin, Smith, & Lovaas, 1993; Rutter, 1970).

Researchers have also come to consensus on outcome for individuals with autism. They agree that the likelihood of a good outcome is poor (DeMyer et al., 1973; Kobayashi et al., 1992; Lotter, 1974, 1978; Wolf & Goldberg, 1986). In other words, individuals do not grow out of their autism. Many do not become fully independent as adults and need some form of support for the rest of their lives (Wolf & Goldberg, 1986). In addition, the social deficits tend to persist even though gradual symptomatic improvements have been demonstrated (DeMyer et al., 1973; Lotter, 1974; Rutter, 1970).

Review of Longitudinal Outcome Variables

Researchers have investigated a multitude of variables to try to predict outcome. In general, these predictive variables can be characterized as within-person factors. Such variables include the severity of symptoms, IQ, the development of early language and useful speech, play/social impairments, gender, neurological damage and electroencephalograph findings, social functioning, and developmental delays (DeMyer et al., 1973; Freeman et al., 1985; Gill-berg & Steffenburg, 1987; Goode, Howlin, & Rutter, 1987; Kobayashi et al., 1992; Lotter, 1974; McEachin, Smith, & Lovaas, 1993; Rutter, 1970; Lockyer & Rutter, 1970; Wolf & Goldberg, 1986).

Lotter's (1974, 1978) assertion typifies the general position: Cognitive skills and the ability to use speech communicatively are the most important combination of variables that predict outcome. A person who has a higher intelligence level and has useful speech will do better than an individual who does not.

The knowledge gained from these studies is valuable. However, little has been learned about the environmental impact on outcome. This information is more consequential to many parents and practitioners than the research on within-person factors that tend to be less amenable to change. Freeman, Rah-bar, Ritvo, Bice, Yokota, and Ritvo (1991) and Freeman, Ritvo, Needleman, and Yokota (1985) determined that cognitive and linguistic variables do not change significantly over time. In addition, most people with autism have retardation (Gillberg, 1990), which is generally stable over time. Thus, information on variables that can be manipulated and are responsive to treatment are more likely to be useful to parents and practitioners. Such variables would be relevant to all individuals with autism, regardless of their level of IQ and language. In summary, good outcomes have been characterized as the achievement of independence and a normal social life. The variables--IQ level and useful speech--have been identified as the best predictors of a good outcome. Unfortunately, these two variables are generally unresponsive to intervention or treatment. Longitudinal studies that identify environmental variables that can be manipulated will be more helpful to parents and practitioners.

To present an argument of the limited use of past definitions of outcome, we conducted two retrospective observations on 46 individuals with autism. The first analysis was based on classic definitions of outcome. Relationships between IQ, communication, social behavior, and achievement of independence were examined. A second analysis was based on a reconceptualization of the concept of outcome.

Initial, Traditional Outcome Analysis

Method

Participants. The 46 individuals in our initial analysis met the DSM-III-R (American Psychiatric Association, 1987) criteria for autism that were used to diagnose autism in all Indiana agencies. All individuals had been diagnosed by an interdisciplinary team of professionals at a university-based developmental disabilities center. The mean age at the time of their diagnosis was 5.2 years. The intake IQ and follow-up cognitive levels are listed in Table 1. Intake IQ level was based on the intelligence test scores noted in clients' records at the time of intake. The intelligence tests were comparable and completed by licensed psychologists in Indiana. The follow-up cognitive level was obtained by parental report on the care giver form, to be described later. Mean age of the individuals at the time of referral to the developmental disabilities center was 8.5 years, and at the time of follow-up (this study), mean age was 17.1 years. The mean follow-up time was 8.6 years. The male to female ratio was 33 to 13 (72% vs. 28%).

Instruments. A combination of measures was used. First, a casebook form was developed to collect data on the status of the participants when they were younger. A review of participant records was conducted and client profiles were constructed and recorded on the form. Data such as IQ level, residential placements, and challenging behaviors were compiled from intake psychological, speech and language, and educational evaluations.

A second form, a parent/caregiver questionnaire, was developed and mailed to gather follow-up information on the individuals. Parents and caregivers provided information similar to that collected in the casebook form, such as current residential placement, cognitive level, daily programs, relationships with others, medical/health status, and challenging behaviors. Seventy-six percent of the respondents were parents, 19.6% were group home staff, and 4.3% were grandparents.

The expanded version of the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) was administered to gather follow-up data on social behavior, communication, and daily living skills. Via telephone, a trained examiner interviewed the parent or caregiver.

Results

Cognitive Level. The IQ test scores collected from the records of participants related significantly to parental reports of cognitive level at follow-up, $\chi^2(4, N = 45) = 16.6, p < .01$ (see Table 1) and suggests a relative stability of cognitive functioning over time (Freeman, Rahbar, et al., 1991; Freeman, Ritvo, et al., 1985). At intake, 73.3% of the IQ test scores of the individuals were within the mental retardation range (<70). At follow-up, 84.7% of the parents reported that their child was functioning within the mental retardation range. Parental reports for the follow-up cognitive levels are considered reliable for several reasons: Parents did not appear to try to present their children in a socially desirable way, their reports were significantly associated with intake scores, and researchers have found that parents are accurate reporters of their child's level of functioning (e.g., Harris, 1987; Schopler & Reichler, 1972).

The follow-up Vineland Adaptive Behavior Scales (VABS) mean standard scores for the 46 participants are listed in Table 2. A t test between the VABS domains revealed that the daily living score was significantly higher than the communication or social scores. In addition, an analysis of variance (ANOVA) showed that follow-up parental report of cognitive level related to the communication and daily living skills (see Table 3). Post hoc analysis using Tukey's HSD revealed that the group with average intelligence had significantly higher scores in these domains. On the other hand, cognitive level did not discriminate among social scores. This is similar to the finding of no relationship between verbal IQ and social scores in Freeman et al. (1991).

Residential and Educational/Vocational Placements. To gain a sense of the achievement of independence of the participants, we collected data on their current residential, educational, and vocational placements. At follow-up, most participants resided at home (56.5%). Of these 26 participants, 14 were over the age of 18. Many of the individuals had lived in multiple residential placements (see Table 4). Thirty participants had been placed outside of the home at least once. The mean number of residential placements (anytime the child was moved out of his or her parent's home) was 3.1, and the mean age first placed outside of the home was 9.5 years. Participants living in the most restrictive settings (e.g., institutions) had a larger number of previous placements (7.33) than those who lived in the family home (1.96), a group home (3.92), or an alternative family' home (5.00). Only 16 participants of a mean age of 13 had never been placed outside of the home. Only 3 individuals were living in a large facility or institution at follow-up. This contrasts sharply with DeMyer et al.'s (1973) study: Out of 120 children with autism (mean age = 12 years), 42% were in institutions.

Most participants--61% (n = 28)--were in school at the time of follow-up; all participants, with the exception of 3, were in segregated classrooms in general education schools and 1 was in a large residential placement out of state.

Of the adults, 61% (n = 11) were receiving adult services. One was in supported employment, 6 were in sheltered workshops, 2 were in activities of daily living programs, 1 was in sheltered and community work, and 1 was in activities of daily living and community work. Four adults were not in programs and 2 were living in institutions.

Relationships with Others. Considering the importance of the link between social skills and positive outcomes (Chadsey-Rusch, 1990; Smith, 1990), we explored quality of social interactions in persons with autism. Parents or caregivers reported how well the person with autism related with other people. Using five categorical descriptions, from quarrelsome to relates caregivers rated relationships with parents, other adults, teachers, siblings, and peers. In the present study, all VABS domain scores correlated directly with peer relationships (see Table 5) and sibling relationships (except for communication). Daily living skills correlated directly with relationships with teachers and other adults. Overall, caregivers reported that individuals with autism had better relationships with parents and adults than with peers and siblings. These findings confirmed those of previous research (Howlin, 1986).

Challenging Behaviors. Casebook information on early childhood behaviors revealed that 56% of the individuals exhibited aggression, 61% exhibited self-injury, 95% exhibited self-stimulation, 35% exhibited compulsive behaviors, 64% exhibited hyperactivity, 20% exhibited eloping or running away, and 43% exhibited pica.

At follow-up, caregivers reported that 53% of the individuals displayed some aggressive behavior, 57% displayed self-injury, 77% displayed self-stimulation, 65% displayed compulsive behaviors, 33% displayed hyperactivity, 13% displayed eloping/running away, and 16% displayed pica (see Figure 1). The number of challenging behaviors noted in the casebook information was directly correlated with the number of residential placements ($r = .33$, $p < .05$).

Discussion

This initial analysis examined the outcome of individuals using traditional outcome criteria. Relationships among IQ, communication, social and other behaviors, and level of independence' were examined. The participants' VABS scores were low overall; 96% had communication and daily living standard scores below 70, and all had social standard scores below 70. The adaptive behavior of this entire sample was comparable to that of Freeman, Rahbar, Ritvo, Bice, et al.'s (1991) low to middle group. The present sample represents a group of individuals who are not representative of the autistic continuum. The participants' overall adaptive behavior was low and their IQ levels varied from average to severe at intake and at follow-up.

As opposed to living independently, all of the 26 adults were living in supported environments such as in group homes, family homes, or large residential placements. The number of residential placements varied from 1 (never moving out of the home) to 10 (for 1 person). About 61% of the individuals moved two or more

times from their parents' home. The number of past behavior problems related significantly to the number of residential placements. Because this relationship is correlational, the relationship between problem behaviors and residential placements remains unclear. In a follow-up investigation of 80 individuals with autism with a mean age of 17 years (similar to this study), Wolf and Goldberg (1986) found that only 31% of their participants were living at home and 69% were living in institutional or group home placements. In this sample, 54% of individuals 17 years or older were living at home.

Parents' reports of their child's relationships with others revealed that adaptive behavior was important for relationships with peers and siblings, but not as much for teachers and adults, and not at all for parents. Howlin (1986) explained that children with autism relate to adults better than to same-age peers because adults are more predictable and more prepared to structure the social situation. Situations that are more structured impose fewer cognitive demands. Thus, it is possible that relationships might improve if supports were provided to peers and siblings.

With the exception of compulsive behavior, challenging behaviors appeared to decrease. Almost twice as many individuals were noted to be compulsive at follow-up than at intake. However, about 20% to 30% fewer individuals were identified as displaying self-stimulation, hyperactivity, and pica at follow-up. Only about 2% to 7% fewer individuals were reported to display aggression, self-injury, and eloping at follow-up. Thus, it appears that even though more individuals were living at home and in other community placements, parents and caregivers were still managing challenging behaviors.

Using the two main traditional criteria of a "good outcome"--the development of a normal social life and the achievement of independence--all individuals would be judged as having poor outcomes. At adulthood, all participants had low VABS standard scores, especially in the social domain. All the adults were living in supported environments such as in group homes, family homes, or large residential placements. Further, many individuals had challenging behaviors.

Despite their social and communication difficulties, however, many of the adults from the present study were working in valued jobs, participating in family and community activities, learning to make choices, and generally happy. Thus the findings of this review, which indicated poor outcomes, led us to question the utility of traditional definitions of determining outcome and to reconceptualize this concept.

Four vignettes of adults from the present sample who were doing well are introduced, and then the variables that relate to their success in adulthood are discussed. These individuals were leading active lives, had individualized supports, and were integrated into their communities. Their outcomes would have been difficult to predict years ago. Moreover, these positive outcomes were rendered invisible when these adults were assessed according to the prevailing, traditional definition of outcome.

Vignettes of Four Participants

Elaine

Elaine is 23 years old and has been living in a group home since she was 14. Her cognitive skills tested in the moderate range on the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) at initial contact and when she was 12. At follow-up, her VABS standard scores were 43 for social, 20 for communication, and 61 for daily living. Her early years were difficult for her family. Her parents divorced when she was 5. Her mother was unable to attend her older sister's school affairs because Elaine often stripped, yelled, and couldn't sit still. Elaine's mom was advised to institutionalize her during her preschool years. Instead, her room and family, including her stepdad and younger brother, became strong advocates for her over the years. They included Elaine in all family gatherings and insisted that she receive positive regard and respect from all. She attended a special needs preschool program for children with autism for 1 year and then a separate school for students with disabilities throughout elementary school. She spent 2 different years outside the family before moving to a group home, one at a university model residential program where she went home each weekend and the other at a facility for people with neurological and physical problems when Elaine was having trouble with arthritis. She has a sense of humor, like her mom, which has created a pleasant interaction between them. She and her mom go out to eat and shop together, especially for jewelry. Elaine loves to wear rings and bracelets like her mom and sisters. Jewelry is often an

opener for conversation. Elaine's world and network widened as she grew. While she was at the group home she attended the local high school in a functional community-based program, where she had several different job experiences. She participated in a number of community activities, such as swimming at the local YMCA, shopping, and continued regular contact with her various family members. Elaine has learned to ride the bus to work and is proud of her accomplishments. Upon graduation she continued to work in a frame shop, and then switched to a bookstore. This job was supplemented with a collating job at a university. When problems arose, her family advocated for her and encouraged collaborative and proactive problem solving. Elaine increasingly expresses her own ideas, and everyone who cares about her has had to listen and remember that she is an adult. Although Elaine has had a number of strong advocates over the years, her mom has been central to bringing a team together as proactive problem solvers and decisionmakers, with Elaine being part of this team whenever possible.

Ed

Ed is 19 years old and still in high school. His cognitive abilities test in the mild/moderate range and his VABS standard scores were 46 for social, 37 for communication, and 76 for daily living. He has had various job experiences, including library and office work, cleaning, and bussing tables. Currently he is working part-time at a direct mail company. The community-based high school program provided Ed with an array of experiences as well as peer tutors and advocates. He moved to a group home when he was 11, and then moved to a group home in another city when he was 14 so he could participate in the well-established high school program there. While at the group home he has participated in many activities, including shopping, swimming, and attending concerts. He recently rode in a 50-mile bike race. Ed has an older and a younger brother, both of whom he sees regularly and with whom he interacts. His mother has been a strong advocate and knowledgeable professional since he was small, and his mom and dad work as a team. As a young child he was extremely active, making it difficult to keep track of him or of what he was doing. He attended preschool and at one time was in a program for children with autism; then he was placed in special education classes for students who had moderate retardation. His communication and social skills have continued to grow with his success. He likes to do activities with people, has a sense of humor, and has even been on a panel to discuss autism.

Andy

Andy is 26 years old. He and his mom have been alone for 2 years, since Andy's father died. He is the youngest of 7 children. At age 13, his performance IQ was in the normal range, whereas his verbal IQ tested at the low/moderate range. His VABS standard scores at follow-up were 27 for social, 28 for communication, and 46 for daily living. Andy was in a segregated school program until junior high school. Then he was in a special education class, participating in choir, art class, and shop, and this situation continued into high school. These classes helped develop his strengths. He was highly successful in 4-H art projects, winning prizes at the county and state fairs. His parents fought to have him included as much as they could and were always strong advocates for Andy. Andy has a great deal of trouble expressing himself verbally, but does better writing or typing. His ability to carry on a reciprocal conversation is extremely limited. In spite of this limitation, Andy is a good worker. He is accurate, quick, and constant. He can be moved from job to job and learns quickly. Periodically, behavior has been a concern in the workshop. Andy has had a few inappropriate interactions there, and has engaged in some repetitive and compulsive behaviors during unstructured time. Andy is a highly visual learner. He responds well to written information about his schedule, changes, rules, and routines. Andy's mother has found "helpers" to keep Andy involved in community activities like bike riding and swimming at the YMCA. Recently she and Andy have attended an aerobics class together, and they go out to eat and shop. They also travel together. As Andy has grown older his mother has had to struggle to keep him involved outside the home and feels she has received little help with this from the local Association of Retarded Citizens. Andy needs supervision and support that she is not always able to provide because she is almost 70 years old and has health problems. Andy lived briefly in a group home the year before his dad died, but both parents felt it was too restrictive. His mom feels that she and Andy enjoy each other now more than ever before, but she worries about his life when she is no longer around. She hopes that he can live in the same house with people who can support him, perhaps in a supported living arrangement. She also hopes that one day he'll have a community job. She was told when he was 2 years old that there was nothing that could be done for him and that for the good of the family he should be "placed." He screamed, took off his clothes, ran away, was a picky eater, and didn't sleep well. He only played with things that he could pin and spent hours looking at patterns. She found an appropriate

preschool program an hour from home that she drove him to and from 5 days a week for 2 years. She started her advocacy back then and has never stopped advocating.

Ellie

Ellie is 24 years old and lives with her parents in a rural setting. Ellie's cognitive scores were in the mild range at intake at age 13. Her VABS standard scores were 46 for social, 89 for communication, and 80 for daily living at follow-up. She works at a day-care center operated by a relative and helps clean up, serve meals, and sometimes reads to the children. In the summer she helps out at the Senior Citizens' Center, where some of the women have taught her some stitchery. She is the fifth of six children and has always been part of the family activities, unless she chose to stay home to cook, clean, or listen to music. The extended family lives in the vicinity, and Ellie took part in 4-H and county fair activities each summer. She was in special education classes in the local school and participated in some general education classes in high school with adaptations. She especially enjoyed home economics, where she cooked, sewed, and ate. As she became an adult, she attended various activities and clubs with her mother, aunt, and sister. Sometimes school was difficult for her, especially when kids made fun of her or someone was mad at her. She spent a year at a university residential model program, going home each weekend, after she developed school phobia and sometimes hyperventilated, making it difficult for her to attend school regularly. Ellie always wanted to do well and was intolerant of her own shortcomings. She is great at imparting her knowledge to others. She has a sense of humor, considers her newly married sister her friend, and writes and calls a number of friends across the age span. She regularly sends holiday cards. She travels with her family and continues to be aware of and learn social amenities, like complimenting and offering. She talks about wanting to drive and live on her own some day, but she is comfortable in her family role. Ellie's mom and dad encouraged her to think for herself and talk for herself. They encouraged independence, choice, and decision making.

Discussion

We contend that these 4 individuals have a "good outcome"--although on the basis of factors other than their achievement of a normal social life and independence. They are happy and productive members of their communities. They are continuing to learn, problem solve, make choices, and express their preferences.

What seemed to be an important predictor of success was that whenever individuals and their families were confronted with challenges, they sought and successfully accessed various supports. For example, when families were told to "place" their young children, their parents sought and created alternatives. Some of the families were the first to push for integration in school and used their natural community and family ties to include and support their child. When families needed residential options, they created them. The families maintained monitoring and input into all the programs their children were in and kept in close contact with their children. They still do. These families identified new opportunities and advocated that their children be part of those opportunities. Family advocacy appears to have been a key factor in successful outcomes for Elaine, Ed, Andy, and Ellie.

At follow-up, Elaine, Ed, Andy, and Ellie were generally happy and participating in activities of their choice. They were active in their communities, working in valued jobs, and interacting with a growing network of people. However, 2 years from now, the picture may be different for them. The balance between risk factors and protective factors must be achieved in favor of supports. Protective factors must outweigh and counterbalance risks (see Figure 2). From our experience with these individuals, it appears that when a person is doing well, supports are dropped or diminished. Indeed, this balance will have to be continually monitored throughout the life of a person with autism.

Everyone depends on supports to keep life in balance. Most people build their supports through family, friends, and community affiliations. For the individuals characterized in the vignettes, support systems were a major reason for their success. Families were actively involved with all of these adults. The group home helped establish and maintain a layer of network of activities and friends in conjunction with their families. How can we argue that these individuals were doing well when they still needed a number of supports?

Expanding the Traditional Concepts of Outcome

As noted, the conventional framework for outcome assessment has identified linguistic and cognitive variables as the best predictors of outcome. These variables, however, do not change much over time and, therefore, are not helpful to parents and educators. Longitudinal studies that clearly document how parents and educators program for individual needs over time are lacking. Variables that are susceptible to mediation need to be the focus of future longitudinal research (Freeman et al., 1991) and include competency in social, vocational, and living skills, as well as quality of life.

Outcome has traditionally been defined as the achievement of independence and a normal social life. Rapin (1991) extended the concept to include the efficacy of treatment, such as early intervention and social skills training. Rapin's more recent characterization of outcome is meaningful because it addresses the effect of environmental variables on the outcome of individuals. She also used the term competence to describe outcome. Here, we argue that competence and quality of life are best achieved by means of environmental adaptations and supports.

Defining Competence

The term competence is used to evaluate the performance of another person (McFall, 1982). It is not the performance itself, but the evaluation of the performance that is judged by someone as competent or incompetent. The evaluative component of competence is important in the context of judging outcomes in autism. When someone is evaluating the competence of another person, the observer's judgment is subject to error or bias (McFall, 1982). Although previous longitudinal studies in autism have been valuable, we now have the conceptual foundation on which to base a reexamination of them--particularly, a reexamination of the bias implicit in them. Researchers have used criteria defining the disability of autism (such as lack of normal social development) for judging outcome.

Including the Concept of Quality of Life

Lord and Venter (1992) have argued that the happiness of people with autism should be considered as an important aspect of the concept of outcome, and Halpern (1993) has argued that quality of life should be used for monitoring individual outcomes. Quality of life is a term used widely in the literature that can be measured both subjectively and objectively (Halpern, 1993; Heal & Sigelman, 1993). Although quality of life measurements have yet to be developed for individuals with autism, Rosen, Simon, and McKinsey (1995) have suggested that quality of life is actually the guiding framework for developing programs, providing services, and evaluating environments.

General knowledge about the course of the lives of individuals with autism is scarce (Freeman, Rahbar, et al., 1991; Freeman, Ritvo, et al., 1985). Relationships among residential and educational history, sensory problems, challenging behaviors, and various supports for people with autism are interwoven and complex. Regardless of the complexity, the investigation of relationships between variables such as education and employment must be considered in outcome studies (Lord & Venter, 1992).

An Alternative View of Outcome

We suggest that "good outcome" is best conceptualized in terms of the interaction of the environment and the person. The environment supplies protective factors such as supports and adaptations that serve to counterbalance risk factors such as environmental and personal challenges (see Figure 2). The relationship between protective and risk factors provides the link between assessment and intervention (Dalrymple & Ruble, 1995). This balance combines with others' judgments of the person's competence and the person's perceptions of his or her quality of life (see Figure 3). The interactions of these variables are fluctuant and never static across a person's lifetime.

As we looked more in depth at the lives of many of the participants in this study, we attempted to extract the components that appeared to be important to their quality of life at follow-up (see Table 6). We tried to translate these into interventions that parents, teachers, and service providers can apply. Clearly, individuals with autism need strong advocates who know them well and enjoy being with them. These advocates help interpret needs into active programs. For the most part, the most constant advocates were parents, with

other people like siblings, relatives, family friends, and service providers being part of a larger support network. Rarely were teachers part of this network, although teachers or principals were at times mentioned as significant in teaching the individual. Perhaps teachers go in and out of the lives of people with autism rapidly due to constant change, making advocacy difficult. Maybe schools and parents have not really learned how to collaborate on behalf of students and too often segment learning and needs. Group home staff were seen as part of the advocacy, particularly if they were in the home for longer periods. Maybe someone involved with home and community living is more likely to become an advocate. Ruef (1994) explained the Turnbolls' Group Action Planning, which "is a dynamic way for people with a disability and their families to make dreams come true using allies with the knowledge, support, and commitment to get things done" (p. 1). This group alliance needs to be considered an essential ingredient for every person with autism from an early age. Too often, the teams that come together on behalf of a person with autism are there to design a program plan, discuss and resolve a problem, or evaluate. There is often tension, a time shortage, and an absence of feelings of creativity or joyfulness. In fact, the participants often feel restricted and anxious or even somewhat hostile.

Because the individual with autism is often judged by others in negative ways, parents may need to become protective and to become strong advocates. Accurate information and proactive training for teachers, so they understand the disability of autism, how it affects each child, and how to design and implement successful programs, will help teachers to be successful in their teaching and be less judgmental toward students with autism and their parents. Teachers must be certain of obtaining the individualized supports for each student. It also appears that students with autism who have a successful outcome have had many opportunities to interact with their peers in school and community activities. Even though the people in the vignettes had at one time attended segregated facilities, had separate special education classes, and had at least one placement out of their home during their previous years, they had all spent their high school years in their neighborhood high school and had participated in various activities with peers. During these years they also participated in community activities through clubs, sports, camps, and with families. We don't know what the outcome would have been with earlier inclusion with peers in school. These individuals were included with their families and in the community throughout their growing-up years. They also attended preschool programs.

Having a variety of experiences is also a key factor in achieving a good quality of life, including growth of independence and the ability and opportunity to make choices. Part of learning to be a responsible adult comes from people believing that you can achieve and succeed and providing you with the supports and adaptations to do so. Each person's strengths and interests were built and expanded on. Their worlds widened as they became older; rather than narrowed. The ability to make choices comes from having an array of preferences built on successful experiences. This tells us that we have to program specifically to increase the repertoire of activities and interests. We have to be proactive to build self-confidence and self-esteem.

Teaching social skills and paying attention to the reciprocal interaction skills that people with autism need to learn cannot be neglected. Quality of life depends on being around other people and being included in activities with others. For these individuals, doing activities with others and being an active participant was important. Familiarity with the settings, with the people, with the activities, and with expectations aided their comfort level and enjoyment. This comfort came from past successful experiences.

Holding a job was important. Others valued this activity for young adults and had conveyed that message to the people with autism in the vignettes. They were all proud of their work. They were busy and productive. Their degree of independence or what they did was not as important as the relationships they had at work and how others valued what they did. In fact, they communicated more about the people in the work settings than about the job.

Therefore, as teachers, parents, and others are planning individual programs for people with autism, it is imperative that social skills be taught and fostered throughout the school years and beyond. Successful interactions and social acceptance are fluid, depending on the situation. It appears that advocates, friends, and family who include, interpret, and facilitate for the individual with autism are vital to their success. Assuring that this circle widens may be an important part of a successful outcome for a person with autism.

Summary

The purpose of this article was to explore another framework for defining and broadening our view of the concept of outcome. Defining outcome as the relationship between an individual's challenges and strengths, environmental stressors and supports, and others' perceptions of competence and self-perceptions of quality of life (see Figure 3) is more likely to yield a better combination of predictor variables than simply measures of IQ and language. The vignettes illustrated the impact that various supports had on these individuals' outcomes. Quality of life may be the individual's perception and confidence while functioning in socially valued roles that are judged by others as competent.

Professionals need to communicate to parents the importance of competence and its relationship to quality of life and outcome. We need to broaden our views in light of new knowledge, better individualized supports, stronger laws, and better ways of providing inclusionary services. Long after diagnosis, when their child has reached adolescence and adulthood, parents often question and wonder if the decisions they made in the past were good ones for their child. These questions are especially likely to arise if their child is having difficulties as an adult. Unfortunately, many parents may blame themselves despite the foggy crystal ball.

Further Study

The interactions between individuals and their environments suggest that future research must address outcomes on variables that can be manipulated. Risk factors such as sensory problems, and the corresponding environmental supports, need to be clearly defined, implemented systematically, and evaluated. Research investigating relevant environmental variables (such as inclusion, supported employment, and positive behavior support) is needed in order to understand the development of competence and quality of life. Finally, quality of life measures, particularly from the perspective of individuals with autism, need to be developed.

We gratefully acknowledge Rebecca Sheer for administering the Vineland Adaptive Behavior Scales.

TABLE 1 Description of Participants

	Initial (n = 45)	Follow-up (n = 46)
Cognitive level[a]		
Average/borderline	12	7
Mild/moderate	24	29
Severe	9	10
Age (years)		
M	8.5	17.1
Range	2-19	7-26

Note. Initial = time of initial contact. One subject didn't have early IQ score. Follow-up functioning level based on parental report.

a χ^2 (N = 45) = 16.6, $p < .01$.

TABLE 2 Mean Vineland Adaptive Behavior Scales (VABS) Standard Scores at Follow-up

VABS domains	M Score (n = 46)	SD	Range
Communication	31.5	18.5	20-103[a]
Daily Living	34.0	18.4	20-80[a]

Social	29.9	12.7	20-61
Composite	29.7	13.4	20-71

Note. A t test of domain scores revealed no differences between communication and social. However, daily living differed from communication, $t = 3.38$, $p < .01$. a Two participants had scores greater than 70.

TABLE 3 ANOVA of Vineland Adaptive Behavior Scales Standard Scores and Caregivers' Report of Follow-up Cognitive Level

Legend for Chart:

A - VABS domains
 B - Caregivers' report of cognitive level: Average (n = 7)
 C - Caregivers' report of cognitive level: Mild/Moderate (n = 29)
 D - Caregivers' report of cognitive level: Severe (n = 10)
 E - Test of significance[a]

Communication	50.57	30.55	20.80	6.84[b]
SD	26.49	16.28	2.53	--
Daily Living	51.57	34.21	21.20	7.12[b]
SD	15.38	18.83	3.79	--
Social	35.43	30.86	23.30	2.21
SD	13.71	13.30	7.42	--
Composite	42.57	29.69	20.80	6.78[b]
SD	15.77	12.89	2.20	--

a Tukey's HSD revealed that average group was significantly different from other two groups.

b $p < .01$.

TABLE 4 Residential Information

Legend for Chart:

A - Current placement
 B - M months in current placement
 C - M age of subject (in years) in current placement
 D - M number of previous placements

A	B	C	D
Family home (26)	136.00	16.04	1.96
Group home (13)	43.40	17.62	3.92
Alternative family for adults (4)	11.25	20.00	5.00
Large residential (3)	29.00	20.67	7.33

Note. Mean number of placements for all participants was 3.10. Mean age first placement outside home = 9.5 years. Sixteen participants have never moved outside of their family home; their mean age is 13.0 years.

TABLE 5 Mean Relationship with Others and Correlation of Vineland Adaptive Behavior Scales (VABS) Standard Score

Legend for Chart:

A - Peers
 B - Siblings
 C - Mother
 D - Father
 E - Teacher/Supervisor
 F - Adults

	A	B	C	D	E	F
M[a]	2.90	3.30	4.20	4.00	3.60	3.20
SD	0.85	0.96	0.92	1.06	1.19	0.87
VABS domains						
Communication	0.36[b]	0.29	0.17	0.06	0.18	0.25
Daily Living	0.56[c]	0.45[c]	0.26	0.24	0.38[b]	0.31[b]
Social	0.41[b]	0.37[b]	0.15	-0.05	0.13	0.22
Composite	0.48[c]	0.39[b]	0.23	0.12	0.27	0.29

a Parents' perception of child's relationship with others was determined by 1 = quarrelsome, 2 = ignores, 3 = inconsistent, 4 = relates moderately well, 5 = relates well.

a $p < .05$. b $p < .01$.

TABLE 6 Quality of Life Indicators to Consider in Judging Outcomes for People with Autism Participate in activities with family members or close friends (e.g., travel, eat out, shop, favorite games or activities, church, dinners).

Included in family/close friends' events and passages (e.g., holiday gatherings, weddings, funerals, births, birthday celebrations, illnesses, and accidents).

Contact with family members and friends as frequently as desired (e.g., make and receive phone calls, write and receive letters, and send and receive cards, visits, invitations).

Active and comfortable in familiar community:

Ride transportation, walk, ride with family or friend, ride bike;

Shop for groceries, clothes, gifts, cards, crafts, needed equipment, personal items;

Choose movies, videos, places to eat, ordering in;

Go to special events: sports, circus, shows, concerts;

Participate in the YMCA, bike club, or other interest or philanthropic clubs.

Work at a valued job to earn money:

Like job and feel good about doing it;
Supported by people on the job;
Can do job competently;
Know performance is good.

Learn about the world through successful experiences with supportive people:

Opportunity to try new activities;
Opportunity to meet new challenges;
Opportunity to meet new people.
Opinions and choices are considered valid and important.

Take responsibility for personal and home chores to the greatest extent possible and take pride in doing this through recognition and contributing to the family:

Bathe, wash hair, shave, style hair, and get hair cut;
Cook, clean, take care of clothes, pick up after self;
Health and wellness--nutrition, weight, medication.

Has own special possessions and personal space to keep as desired and has time and space to be alone when desired.

Makes choices about purchases and manages own money to the greatest extent possible.

Receives enough information to make valid choices and not have to refuse them because of lack of information, lack of experience, or lack of support.

FIGURE 1. Percentage of individuals with challenging behaviors.

	Intake	Follow-up
Aggression	55.6	53.3
Self Injury	61.4	56.8
Compulsive	34.9	65.1
Self Stimulation	95.3	76.7
Hyperactivity	64.3	35.7
Eloping/Running	20	13.3
Pica	43.2	15.9

DIAGRAM: FIGURE 2. The balance between risk factors and protective factors in autism. Note. From Technical Assistance Manual on Autism for Kentucky Schools (p. 10), by N. Dalrymple and L. Ruble, 1996, Frankfort: Kentucky Dept. of Education. Copyright 1996 by Kentucky Dept. of Education. Reprinted with permission.

DIAGRAM: FIGURE :3. A framework to consider {or outcomes in autism.

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