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An alternative view of outcome in autism. By: Ruble, Lisa A., Dalrymple, Nancy J., Focus on Autism & Other Developmental Disabilities, 10883576, Spring96, Vol. 11, Issue 1

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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 rcconceptualized.

[Traditional Definitions of Outcome](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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, chi2(4,N = 45) = 16.6, p < .01 (sec 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 arc 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 < .os).

**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 has 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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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 morn, which has created a pleasant interaction between them. She and her morn go out to eat and shop together, especially for jewelry. Elaine loves to wear rings and bracelets like her room 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 morn 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 @roup 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 dally 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, ct 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 Turnbulls' 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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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 chi2 (N = 45) = 16.6, p < .01.

[TABLE 2 Mean Vineland Adaptive Behavior Scales (VABS) Standard Scores at Follow-up](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "TABLE 2 Mean Vineland Adaptive Behavior Scales (VABS) Standard Scores at Follow-up )

M Score

VABS domains (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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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).](http://web.ebscohost.com/ehost/detail?vid=18&hid=123&sid=240d311e-48ea-45be-b829-184fc61ba819%40sessionmgr115&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1zaXRl" \l "toc" \o "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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