

The International Journal of Special Education
2005, Vol 20, No.2.

THE QUALITY OF LIFE OF A CHILD WITH ASPERGER'S DISORDER IN A GENERAL EDUCATION SETTING: A PILOT CASE STUDY

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This pilot qualitative case study was designed to investigate how the quality of life (QOL) of a child with Asperger's Disorder was impacted by her placement in an inclusive education setting which provided no specialized social skills instruction. Direct and indirect data were gathered and examined regarding themes that centered around QOL dimensions and exemplary indicators derived from the body of literature regarding QOL measurement for persons with disabilities. Positive results included participant satisfaction with physical safety, teacher acceptance, and access to needed materials. Other findings indicated the need for social skills instruction and individualized instruction in non-applied abstract learning activities. Additional findings from the study demonstrated the need for a more comprehensive individualized education program (IEP) and more rigorous implementation of the IEP.

For several decades, quality of life (QOL) measures have been used to evaluate programmatic and other outcomes for people such as those advancing in age (Newsom & Schulz, 1996), with health concerns (Renwick, Brown, & Nagler, 1996; Walker & Rosser, 1987), with mental illness (Katschnig, Freeman, & Sartorius, 1997; Priebe, Oliver, & Kaiser, 1999), and with developmental disabilities (Brown, 1997; Schalock & Siperstein, 1997). Methods of measurement and identification have included the use of questionnaires, rating scales, multivariate research designs, and interviews, and these measures have taken place in various institutions, hospitals, and community settings (Schalock & Siperstein, 1996). Currently, QOL measurement for persons with disabilities is based on a conceptualization embodying personal perspectives, equal opportunity, empowerment, and acceptance, all within the context of the living parameters that are valued and desired by everyone in general, and its measurement conducted using multifactored approaches (Schalock & Siperstein, 1996).

Though current QOL research has been conducted in school settings with various populations of students (Edwards, 2003; Gilman & Ashby, 2003; Lapan, Gysbers, & Petroski, 2003), there are few examples of QOL research regarding children with Asperger's disorder (AD) in general (Macleod, 1999; Nydén, Paananen, & Gillberg, 2000), and even fewer regarding this population in the context of public schools (Carrington & Graham, 2001). However, salient research has been conducted in the areas of academic and social supports for children with AD in public schools (e.g., Gross, 1994; Safran & Safran, 2001; Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002; Gutstein & Whitney, 2002). These areas are certainly associated with a child's overall QOL, but they are not the whole of the concept, especially regarding how this specialized line of research has over decades evolved and grown. Academically based measures alone are inadequate to investigate the affective results of the interaction among children with AD and the many people and variables within educational environments.

Children with AD pose some unusual challenges to educators because they often embody great strengths as well as great challenges. Children in general are sometimes viewed either in light of their greatest strengths or with much emphasis placed on their greatest challenges, both views ignoring the possibility of a wide variability in proficiencies among skill sets. Where marked

strengths are present, the assumption can be made that other, commonly associated skills have been acquired and are being maintained at a high level of proficiency (e.g., the presence of highly developed intellectual skills can lead to erroneous assumptions regarding social skills). Where marked challenges are present, the assumption can be made that performance deficits are wilful acts with premeditated intent (e.g., *He has other behavioural challenges, and he knows how to perform the skill. Therefore, his lack of performance is also a manifestation of challenging behaviour.*). The presence of these assumptions can be one of the factors greatly affecting the shape, types, and/or availability of the educational supports offered to children. This is especially true with those children who embody both great strengths and great challenges, as is often the case with children with AD.

Approaches to Educating Children with Autism

General Focus

Since the shift from institutions as primary placements to inclusive educational settings in community schools, the delivery of educational services to children with developmental disabilities has had a focus on the methods of service delivery, though not necessarily on the overall quality of services (Wheeler, 1996). The overall movement/trend toward improving the quality of services provided has involved the measurement of specific educational outcomes as related to personal and family satisfaction and home, school, and community validations of the impact of educational training.

Specialized Approaches

In combination with this focus on socially valid outcomes, children with autism have also received specialized education aimed at addressing the challenges of their particular disability. According to the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV) (American Psychiatric Association, 1994), such challenges include a significant impairment in social interaction skills, a significant impairment in communication and/or language skills, and behaviour patterns, interests, and activities that are repetitive and stereotyped. In addition, the DSM-IV notes that most cases of autism (75%) are associated with mental retardation, and can be accompanied by attention deficit hyperactivity disorder and various forms of self-injurious behaviour. Educational programming for these students has typically concentrated on four main areas of instruction that directly parallel these challenges: (a) behavioural interventions and supports (for dealing with challenging behaviours such as self-injury and perseverative preoccupations), (b) communication and language training, (c) specialized instructional delivery (e.g., direct instruction, discrete trial teaching, and task analysis), and (d) building social skill competencies (Scott, Clark, & Brady, 2000). The comprehensive nature of these approaches was designed with the general purpose of increasing the societal options and freedoms of children with autism, especially as they relate to school, home, and community environments.

Socialization and Quality of Life Measures

Socialization Needs

Intimately connected with the building of social skills competencies in children with developmental disabilities is the concept of *quality of life*. In fact, in beginning to build an understanding of quality of life (QOL) as a concept with important implications for the education of children with autism, it is useful to examine the types of socialization needs addressed by many social skills programs designed for children with autism. Broadly, these needs include: (a) learning the rules of personal proximity, (b) using both objects and one's body appropriately when interacting socially, (c) learning to initiate and appropriately maintain social interaction, (d) controlling behaviours that are repetitive and stereotyped, and (e) readily adapting to environmental change (Olley, 1986). It is easy to imagine how deficits in these areas could negatively impact almost every aspect of a person's life, especially educational interactions vital for access to learning and other school-based opportunities.

Definition and Measurement

Schalock (2000) defined the concept of QOL as a multidimensional, interactive process in which certain primary dimensions have individualized levels of importance that tend to change

throughout a person's life. Identified from 30 years of research, the eight core dimensions of QOL were given as follows: (a) emotional well-being, (b) interpersonal relations, (c) material well-being, (d) personal development, (e) physical well-being, (f) self-determination, (g) social inclusion, and (h) rights. The most commonly used measure of a person's QOL has been personal satisfaction (Wehmeyer & Schalock, 2001), an approach that has several major advantages (such as obtaining data in the person's own words that can be commonly shared among all involved). However, Schalock (2000) pointed out that although personal satisfaction has its advantages, several of the core dimensions do not readily lend themselves to investigation through this type of approach (i.e., material well-being, personal development, physical well-being, and social inclusion). For the evaluation of these dimensions, he suggested using functional behavioural assessment, a procedure involving rating scales, observation of the participant, and structured interviews. As in measures of personal satisfaction, a student would be evaluated across the particular set of indicators for each of the dimensions investigated.

Asperger's Disorder is Unlike Autism

Along with autism, Asperger's disorder (or syndrome) falls under the broad spectrum of disorders known as pervasive developmental disorders (PDD). Many professionals, however, consider it a totally distinct and separate PDD (McLaughlin-Cheng, 1998), and, unlike autism, AD entails no cognitive impairment or delay in language acquisition (APA, 1994). In many aspects, these children operate at an average or above average level of intellectual functioning, or IQ, and have adequate expressive language abilities, though more intense probing often reveals difficulties with problem-solving, critical thinking, and use of pragmatic language (Scott, et al., 2000).

Regular Classroom Placements

Due to the presence of many typical or above average abilities in intellectual and communicative functioning, these children are most often placed in regular education settings, at least until they reach high school. In a study with 40 purposively sampled participants initially diagnosed with AD at a university medical center child development program (mean age = 7.9 years; mean IQ = 123), Church, Alisanski, and Amanullah (2000) found that 80% of the elementary aged children spent the entire day in a regular education setting, though some (15%) required the presence of a one-to-one aide as support. This percentage dropped to 69% for middle school, and it dropped dramatically to 40% for high school. The reason cited for these increases in specialized placements was said to be related to increases in challenging behavior, including reports of difficulty in reading social cues, non-age-appropriate social interaction, and failing to understand the consequences of one's actions.

Asperger's Disorder is Like Autism

Whereas some consider AD a totally distinct and separate PDD, others treat it as synonymous with high functioning autism, and the debate as to who is correct is ongoing (McLaughlin-Cheng, 1998). Part of the confusion lies in the similarities that AD has with autism, most notably the presence of specific, significant social skills deficits. Like children with autism, children with AD display deficits in the following social skill areas: (a) learning the rules of personal proximity, (b) using both objects and one's body appropriately when interacting socially, (c) learning to initiate and appropriately maintain social interaction, (d) controlling behaviours that are repetitive and stereotyped, and (e) readily adapting to environmental change. It would seem that as a matter of course the same kinds of social skills programs used to instruct children with autism (with appropriate modifications) would be used to train children with AD, but this is often not the case. In their study, Church, et al. (2000) found that only 6 of the 26 elementary-age children with Asperger's placed in regular classrooms received any type of formalized social skills training. Similarly, Lindblad and Loeffelhardt (1992) cited surveys from 22 parents whose children have AD. Overwhelmingly, the parents surveyed thought that educational services and supports for their children were very limited, a trend that they connected to a lack of knowledge regarding high functioning children with developmental disorders.

Quality of Life and Children with Asperger's Disorder

The Potential for Failure and Frustration: A Justification for Action

Even with adequate aspects of intellectual and expressive abilities in place, good social skills are vitally important for a student's successful performance in school. This importance increasingly intensifies as students move closer to adolescence and young adulthood, a time when social relationships provide the basis for most of what is exchanged in integrated educational and social processes (Tantam, 1991). Social skills instruction has been identified as the most important area of need in children with AD, yet it is the area least often addressed (Myles & Simpson, 2001). Choosing to ignore this need has been found to significantly impact QOL factors such as peer friendships, relationships with teachers, and self-esteem (Myles & Simpson, 2001).

Taking these facts into consideration (especially in light of the findings of Church et al., 2000), placement in inclusive classrooms with few specialized services and supports could very easily be responsible for increased levels of frustration and anxiety. These frustrations may then result in an increase in challenging behaviour that is positively correlated with increase in grade level, further resulting in more restrictive placements for these students as they move through school. Children with AD will often quietly stand by and try to fit in during school situations that severely tax their limited social skills, giving the impression that all is fine while at school. However, described by Attwood (1998) as a "Jekyll and Hyde" phenomenon, these children often will, upon returning home, release the pent-up frustrations of the day, leaving teachers thinking all is fine, parents wondering exactly what they are doing wrong, and the root cause of the behaviour unidentified.

Summary and Research Questions

Though unlike autism in significant ways, AD is like autism in ways that can significantly impact a child's educational success. However, due to high functioning abilities, it is often assumed that these children need few or no supports to operate optimally in a regular classroom. Data revealing increasingly restrictive educational placements as these children move through school, a similar increase in problem behaviours, too few instances of direct social skills training, and parent dissatisfaction with access to school-based supports, all suggest that social skills deficits in these children are not being adequately addressed. Furthermore, considering that the appropriateness of educational programs for children and adults with developmental disorders (including mental retardation with concomitant autism) has been evaluated through the examination of participants' QOL, it becomes relevant to investigate the QOL of these children as it relates to factors in the school environment, specifically for the purposes of: (a) evaluating how and to what extent the QOL framework may apply to their situations; (b) finding out how and to what extent a lack of direct social skills instruction may impact their QOL; and (c) making practical recommendations aimed at increasing the educational options, freedoms, and overall success rates of these children. Following this line of reasoning, the present study sought to extend the approaches taken in similar research by investigating the following questions: How do the QOL dimensions (as identified in related research) apply to what is occurring with a child with AD being educated in a general education classroom? What do QOL and other indicators reveal about the appropriateness of the educational environment provided for this child? Lastly, what do these findings imply?

Method

Case methodology was used to approach the research question and sub-questions in regard to events occurring at school, the participant's perceptions of these events, and the schoolwork completed by the participant. Even though previous studies have investigated Schalock's (2000) core dimensions of QOL in children with developmental disabilities other than AD, an approach using this descriptive method was well suited to this study because no previous study has focused on these aspects regarding this particular population of children. In addition, the case study method was chosen because it provided a thorough investigation of the participant and her school environment, allowing the investigator to probe indicators of Schalock's dimensions more deeply and to also look beyond them for new and valid information.

*Context**- Home.*

The participant's home was chosen for the collection of interview data. It was located in a middle class, suburban neighbourhood. The participant lived with her two parents (both in their 50s), one dog, and two cats in a three-bedroom brick home. The participant preferred this setting for the interview because of its relative comfort, and the researcher thought that it would be a safe location for the participant, one conveniently outside the busy school environment.

- School.

The participant's school is a K-4 school that served approximately 518 students, 94.5% of whom are white. In addition, 2.5% are African-American, 2.1% Hispanic, 0.2% Asian, and 0.7% Native American. Though the numbers tested for special education are similar to national averages (10.6%), the number of students receiving free and reduced lunch is high (46.1%). State report card achievement data for 2001 gave the school an A in math and Bs in reading, language arts, and science. Social studies and 4th grade reading each received Cs.

Participant.

The participant was a 10-year-old Caucasian girl with Asperger's syndrome who, except for one hour of speech therapy per week (in the area of pragmatic language), was being educated in a general education 4th grade classroom. Instructional modifications/accommodations listed in her Individualized Education Plan (IEP) included abbreviated assignments, additional time to complete assignments, provision of special study guides, dictation on standardized tests, and the presence of a full-time aide. She participated in grade-level work in all subjects, and her IEP indicated full participation in all state- and district-mandated assessments.

Purposeful, typical case sampling (Patton, 1990) was used to select the participant. She was also chosen primarily because of her disability, age, and grade placement. Her parents were contacted through a state-funded project that had been involved in her intermittent assessment and follow-up since first grade. Both parents agreed to allow her participation and to provide a copy of her IEP and samples of her schoolwork.

Data Collection

Data were collected through three sources: (a) a structured interview with the participant, (b) a series of two observations of the participant in the school environment, and (c) the collection of permanent products such as her IEP and samples of her schoolwork. Each was guided toward both known QOL dimensions and toward the discovery of additional informational inferences.

Table 1
Data Types and Sources

Data Type	Source	Example(s)
indirect	interview	structured interview with participant (based on QOL dimensions and relevant indicators)
direct	observations in school settings	mathematics, English, physical education
permanent product	home and school	participant's IEP, math and other worksheets, writing samples, standardized test scores, pictures, stories

Interview.

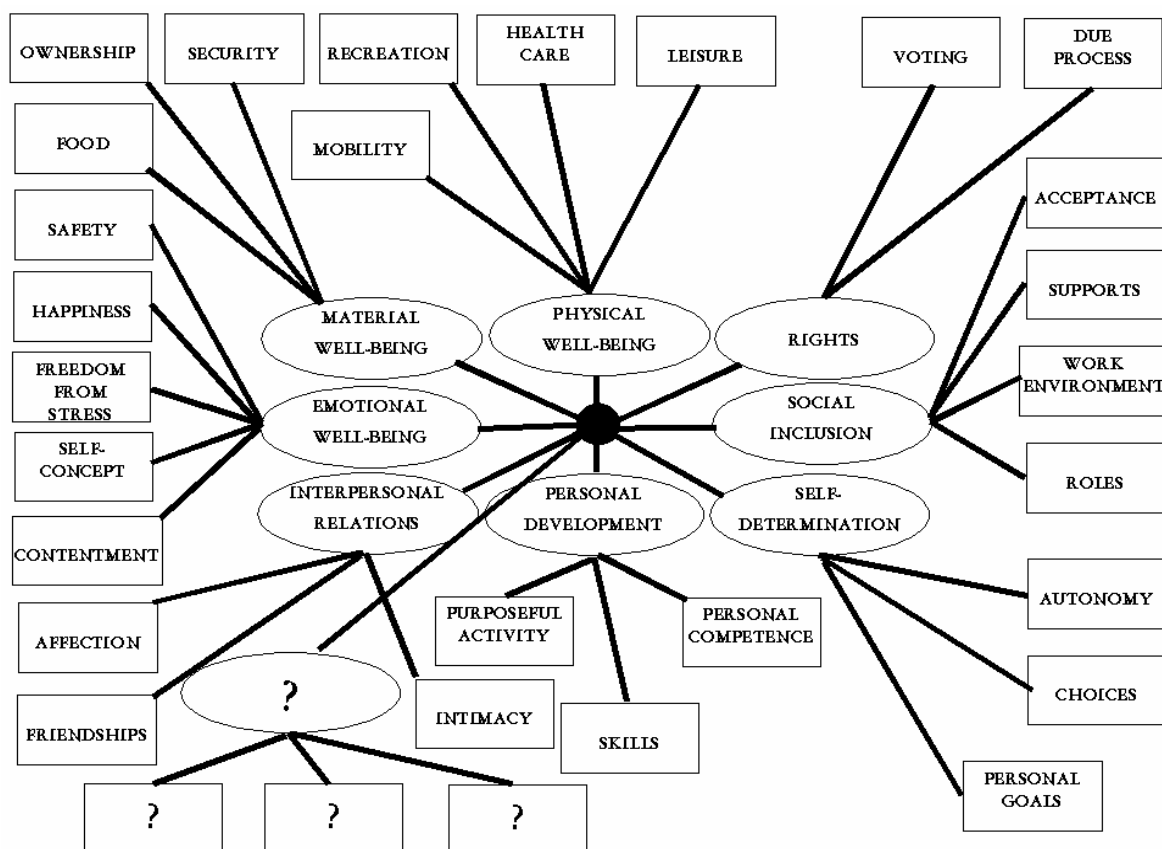
The interview was constructed to try to understand QOL issues from the viewpoint of the participant. Although the primary scope of the items was provided by Schalock's (2000) framework (refer to Figure 1), the interview was designed to both test the situational validity of

these dimensions as well as draw out more information related to participant feelings and thoughts regarding school people and events.

The interview was composed of ten sections addressing the following: (a) open-ended, general indicators about life satisfaction, (b) the eight QOL dimensions applied to the school setting, and (c) open-ended extenuation of the participant regarding any other thoughts and feelings about school. In addition to this, sections dealing with the QOL dimensions began with an open-ended description concerning the particular subject of the section, where applicable. For instance, the section regarding the extent of the participant's social inclusion began with the following: *Think about all the things you did at school on one of the days last week. Describe how included you felt in classroom activities, both by the teacher and by other students.*

Each QOL dimension was explored through questions regarding the provided indicators most relevant to the school setting, activities, and social structure. For instance, self-determination was explored through questions about autonomy, choices, and personal goals, such as: *What kinds of decisions are you allowed to make concerning what you do at school? Are you satisfied with the types of decisions you are allowed to make at school? What decisions would you like to be able to make?*

Figure 1
Quality of Life Dimensions and Indicators Relevant to the Elementary School Setting
(adapted from Schalock, 2000)



The interview was conducted in the afternoon and lasted approximately one hour. It was conducted while sitting on the sofa in the participant's living room. The participant's parents remained in another part of the house and kept the pets from distracting the interviewer and interviewee.

Observations.

A series of observations was conducted for the purpose of comparison and contrast with interview data, to observe the specific topography of participant interactions at school, and to gather data across varying times of day and types of school activities. For instance, observation one was conducted solely in the participant's classroom during spelling and English instruction and lasted approximately one hour, and observation two was conducted in the classroom for approximately 50 minutes and then in the school gymnasium for approximately 35 minutes more. During this observation, the classroom activity was mathematics instruction, and the gym activity was jumping rope.

During the first observation, the emphasis was on collecting as much information as possible regarding the settings and the interactions of everyone present. During subsequent observations, a more focused approach was taken. Observations concentrated on events and interactions revolving around and directly and indirectly impacting the participant, especially in regard to QOL indicators. All observations paid attention to particular sensitising concepts for the purpose of orienting fieldwork (Patton, 1990), including setting, social environment, planned and informal interactions, native language, nonverbal communication, unobtrusive indicators, and what does not happen.

Permanent product collection.

Documents were collected for the purpose of comparison and contrast with interview and observation data, especially in regard to autonomy, choices, personal goals (indicators of the self-determination dimension), skills, personal competence, and purposefulness of activity (indicators of the personal development dimension). The documents collected included the participant's IEP and work samples from school, such as tests, writing assignments, and English, spelling, and mathematics assignments. Documents were obtained from her parents, who were asked to provide a representative sample of her work across subjects and response types.

Data Analysis

First, the interview audiotape was transcribed and checked for accuracy. Next, observation field notes were expanded with richer detail, initial thoughts regarding interconnections with interview data, and the feelings of the observer regarding the perceived tone of social interactions and the overall classroom atmosphere. Lastly, documents were organized according to type (i.e., by academic subject) and examined for any historical, demographic, and/or personal information unavailable from other sources (Glesne, 1999).

Data triangulation (Patton, 1990) was used to compare findings and minimize the weaknesses of singular sources of data. For instance, interviewing allowed the researcher to go beyond what was observed by examining the participant's internal perceptions, providing some balance to the interviewer's perceptions of the external. Also, observation allowed a check on what the participant reported in the interview. Lastly, the documents allowed corroboration of the other two sources and provided information the researcher did not think to ask about.

Next, comparative pattern analysis (Guba, 1978) was used to find recurring regularities in the data. The resulting categories were then examined in regard to internal homogeneity and external heterogeneity, providing the classification system by which the bulk of the data were then meaningfully organized.

Last, a logical analysis of the data was conducted by organizing interview, observation, and document data into categorical matrices, allowing categorical cross-classification for the purpose of deriving salient sensitising concepts (Patton, 1990). These matrices were then used to describe linkages, themes, and patterns among the various classroom procedures and the various outcomes experienced by the participant. The resulting patterns and themes were compared to other aspects of the interviewee reports, observational data, and document information in order to confirm their accuracy.

In analysing the data, it was discovered that several major forces were interacting to shape the participant's overall classroom experience. Though not all of equal power and influence (i.e., participant perceptions of need versus classroom-based perceptions of need), the three main

categories that emerged from the analysis procedures seemed to result in strong interaction effects producing, in some cases, unplanned outcomes. The first category, *participant-defined needs*, referred to the areas discovered to be of primary concern to the participant. This category was based on data from one source, the participant interview. The second category, *document-defined needs*, referred to aspects cited as important in the various collected documents, primarily the participant's IEP. The last category, *school-defined needs*, referred to the areas of importance as defined by the expectations and events in the participant's school environment. This category was mostly based on observation data gathered in the classroom and gymnasium. In order to be considered and confirmed as a relevant category, a particular classification of data had to logically support the existence of all other proposed classifications as well as be supported by multiple instances from the other data sources.

Findings

The findings that follow are discussed by category. Under each category, four main areas are given that relate to the participant's QOL. While other QOL dimensions emerged from the data (see discussion section below), the four given dimensions were the most strongly indicated as well as being those most directly involved in forming the categories themselves.

Table 2
Flow of Research and Outline of Findings

Data Source	Parallel Theme Identified	Strongly Indicated QOL Dimensions Across "Needs" Definitions	Main Participant Themes in Context of QOL Dimensions and Indicators			
			<u>QOL Overlap</u>	<u>Dimensions Not Verified</u>		<u>Additional Indicators</u>
				<u>Of Seeming Relevance</u>	<u>Of Seeming Irrelevance</u>	
structured interview	participant defined needs	physical well-being social inclusion				
observations	school defined needs	interpersonal relations	physical well-being * mobility * leisure	self-determination * purposeful activity * personal competence	self-determination * autonomy * choices	physical well-being * kinesthetic learning
permanent products	document defined needs	personal development	material well-being * food * work materials	interpersonal relations * friendships		interpersonal relations * social play rights * academic assistance
			rights * voting * due process			
			social inclusion * acceptance			

Physical Well-Being

Participant-defined physical needs.

Interpretation of the interview data revealed that the participant seemed satisfied with the opportunities for mobility provided by recess, and in fact, she named it as one of the best things about school (along with snack time and lunch). She said that it made her body feel better *by running around and stuff*. However, she was particularly dissatisfied with the amount of mobility she had within the classroom. For example, when asked if she thought she got to move around enough while in the school building, she replied that she did not and that, *I always have to sit [in] a seat*. Also, she thought that too few opportunities for free time were available, and she once again mentioned recess, this time as an opportunity to do what she wanted to do. However, after this last statement about recess, she disappointedly added, *It [recess] is almost after school*, indicating that she would like to get such opportunities throughout the day as well. The only other free time activity that she mentioned was also portrayed as a possible but less than optimal opportunity for needed leisure time. After being asked why she thought she did not get enough

free time while at school, *centers* were described as free activity spots in the classroom where students could engage in academic and other types of games (math center, reading center, etc.). She then expressed the answer to the question by adding, *...but we have to get all our work done before we go to centers*, indicating her disappointment with the system. Her lack of contentment with classroom mobility mirrored how she regarded opportunities for free time: She thought recess was the only way she got these needs met.

School-defined physical needs.

Interpretation of the observation data revealed that there was a strict division between the types of student needs provided for within and outside of the classroom. The participant had little mobility and no leisure activity while in the classroom, and there was little sign during the observations that such activities were part of the normal routine. While other children in the classroom periodically moved about to turn in work, pick up new work, or talk to the teacher, the participant had all work delivered to and picked up from her desk. Questions about assignments were either answered by the aide or taken care of when the teacher approached the participant's desk. On more than one occasion, the participant rose from her seat a bit in response to a teacher directive to pick up a new worksheet. Her aide quickly got up, got the worksheet, and delivered it to her desk. As for free time, the class moved at a quick pace from one activity to the next, providing only one observed three-minute opportunity for students to access centers. Observation times were worksheet heavy, with three multi-page worksheets in one 50-minute period and 4 in another 50-minute period. During the observation periods, the participant did not complete her work in time to engage in center activities, though other children were witnessed doing so each day.

As for recess, it was indeed the very last activity of the day, taking place just before children returned to their classrooms to get their belongings and go home. During one observation, the participant attended a jump rope activity in the school gymnasium, and there physical mobility was definitely sanctioned. However, she did not fully participate in the activity, making a few attempts at jumping the rope a single jump at a time and only speaking to one or two students exclusively. She did, however, get the chance to be up and walking about, and, at times, she ranged the span of the gym floor, seeming to enjoy the mobility (as evidenced by her facial expression and sometimes energetic body movements).

Document-defined physical needs.

Interpretation of permanent product data revealed that, although explicit needs definitions did not preclude attainment of physical needs by the participant, implicit needs definitions often did. Her IEP stipulated that the aide *will go on field trips* with the participant and take dictation from her as both classroom and testing accommodations/modifications. There was no mention of the aide's role being that of an academic tutor to answer questions or a personal assistant who takes care of getting work and turning it in for the participant. These barriers to physical activity in the classroom seem to have developed independently of IEP requirements, perhaps as misinterpretations of the document's original intent or as a means of limiting social interactions with other students, thus avoiding potential problems or conflicts.

However, needs definitions implicit or inherent in other documents did preclude the attainment of physical needs by the participant. Analysis of work samples from school supported observations of a worksheet heavy learning environment. Out of 23 total examples deemed by her parents as representative of the participant's schoolwork, 17 (or approximately 74%) were worksheets. Evidence of hands-on, active work such as products and projects (as opposed to low-activity paperwork) were all but non-existent, with the only examples of self-made books, illustrations, and other such products being from home. Since working on worksheets is a mutually exclusive activity to all but fine-motor body mobility, and since document evidence revealed a worksheet heavy environment, it was concluded (with supporting interview and observation evidence) that

the type of work most often done by the participant was an important factor in unmet physical needs in the classroom.

Social Inclusion

Participant-defined social needs.

The participant indicated that the teacher loved and accepted her in the classroom, stating that, *She tells me that she does not want anybody to hurt me or anything; she tells me not to let anybody hurt me.* She also thought that the teacher provided adequate support and encouragement for her to be socially included in the classroom. One example of this was embodied in a quote she gave from her teacher, *You will never learn if you don't try.* Similarly, the participant felt that the social working environment was adequate, relating a recent instance of helping with the completion of a group science project. Also, she described two instances of getting to take on differing roles in the classroom, such as being a *paper passer*. The other instance she described was only a one-time role, for she said, *I was the flag holder person once.* [researcher's emphasis]. However, much of this seeming lack of substantive, inclusive roles in the classroom was perhaps due to imposed limitations for the age and developmental levels present in an appropriate 4th grade setting.

Though she felt accepted by the teacher, the participant did not feel completely accepted by the other students in class. Except for two students she named who play with her at recess and *like to have [her] as a friend*, the participant indicated that acceptance by the other children in class was uncertain. In fact, she related a recent instance of teasing by two male students who puffed air through drinking straws, pretending to shoot paper balls at her. When asked if these students teased other students or mostly her, the participant replied that they mostly tease her, *But I'm used to it; they do it all the time.*

School-defined social needs.

Opportunities for social inclusion were scarce and of low quality during classroom observations. In two, 50-minute class periods, the participant was called on for an answer only once (out of the 15 other students in the room), and this particular instance was negative, with the teacher prolonging the wait time after the questions and ending by stopping instruction, coming back to the participant's desk, and, with a stern expression on her face, quietly telling the participant something. Across the observations, the participant engaged in a peculiar activity five different times. When the class was prompted for questions or answers, she would sometimes quickly raise her hand and just as quickly withdraw it again. This was perhaps due to the fact that she had a question or wanted to be included in the discussion but had some reservations about doing so. There was no evidence of group work during these times, and, though several students got jobs to perform in the classroom, the participant was never asked to participate in these activities.

During recess, the participant had many more rich opportunities for social inclusion, though there was no direct process to promote her active involvement in them. As the other students jumped rope with no formal direction, the participant sometimes followed the physical education teacher about the gym as the teacher spoke with students. The participant's only prolonged conversation and social interaction during all of these 35-minute periods was with one boy exclusively (one of the two students she named that made her feel accepted). When this boy was with her, she played and directed her full attention toward him. When he left her to talk with other classmates, she waited for him to return and did not follow. Their interaction often moved away from the action in the center of the gym and toward one wall, where they were near relatively few students.

Lastly, there was confirmation that she was not fully accepted by other students. There was an incident in which two boys teased her by touching her and running. The participant exhibited stern facial expressions and closely followed one of the boys toward the back wall of the gym,

placing her face close to his as he stopped and turned toward her. However, the confrontation ended when the announcement came to prepare to go back to class.

Document-defined social needs.

The only document-defined need related to social inclusion was found in the participant's IEP. Included was a provision for *preferential seating* in the classroom. The manifestation of this provision was seen in the placement of her desk at the end of a row in the back of the room, very near the teacher's desk. Students filled all the other desks in the room except for the one desk next to the participant. The intended reason for this particular interpretation of the provision was unclear, but an unintentional result was physical isolation from the other students in class.

Interpersonal Relations

Participant-defined interpersonal needs.

The participant was satisfied with the levels of intimacy available to her at school. Once again, she referred to the two students whom she said played with her at recess. She felt very close to the boy and named the girl and the teacher as people whom she would feel safe talking to about her thoughts and feelings. Her reasons for choosing these people above others echoed her reasons for feeling accepted by them. She repeated that the teacher loved her and that the two students played with her at recess. However, she did qualify her standards for intimacy by indicating that she would not tell just any classmate her thoughts and feelings, for, *Some [classmates] are [nice to me], but not all.*

Concerning affection in her school relationships, the participant named the same girl and her teacher again, saying that she knew her teacher cared for her because, *She believes me when I tell her a kid teases me.* As for friendships, the participant named the same girl as her good friend (*She talks to me and tells me it's okay when I have a bad day and stuff.*) and her teacher as her best friend at school (*Mrs. B. gives me help on stuff, and she lets me erase the board sometimes.*).

Also, the participant had little awareness of reciprocity in her relationships, being more aware of how others were friendly than how she initiated or returned friendly actions or words. For instance, when asked what she did to make her female friend like her, she replied, *Not sure—try to be sweet,* and then when asked what she did when she was trying to be sweet, she replied, *I talk and stuff; I don't know.* In addition, she showed little awareness of the need for initiating relationships. For example, when asked how she let her friends know that she liked them, she replied, *Well, I play with them back.* When asked about the last friend she made, she described how the other child initiated the contact with an invitation to play. This was repeated when she was asked about another friend she mentioned, indicating a passive role by saying that she did not make the first contact but that, *the teacher put her in the desk next to me.*

School-defined interpersonal needs.

School-defined needs either placed a low priority on interpersonal relations (as in the classroom) or provided opportunity without guidance (as in the gymnasium). Also, intimacy, affection, and friendships for the participant were not only limited by the classroom environment, but they were also limited by her interpersonal skills. To some extent, classroom limitations in these areas are normal, especially considering the emphasis on the business of learning. However, physical isolation from other students, a lack of cooperative learning activities, and an emphasis on worksheets all contributed to limitations in developing needed interpersonal relations. In addition, reports of limited friendships, limited interactions in social situations, and difficulty initiating friendly interactions all point to interpersonal skill limitations.

Document-defined interpersonal needs.

According to her IEP, the only special education service the participant received was in the area of pragmatic language (one hour per week), an area related to reading social cues and using language conventions appropriate to the situation. Pragmatic language can have an important influence in interpersonal relations, for the personal titles used, level of familiarity, tone and

inflection, use of polite words such as *please* or *thank you*, etc. can all affect how one is perceived and accepted by others.

Personal Development

Participant-defined development needs.

The participant was satisfied with the skills she learned at school, citing mathematics as useful in helping her father measure materials when building things at home. Her art was also important to her (she mentioned several times during the interview that she enjoyed drawing), for the school-related skill she named as important was learning how to fold origami. Social studies was the subject for which she had the least regard. In fact, she named social studies as being the thing she least liked about school. Her understanding of the utility and purpose behind this subject was unclear and seemed to be tied solely to the textbook, as evidenced by her comment, *Well, we have to do our book a lot. After the teacher goes over it, we have to think about it, and I don't like it.*

In the area of effectively addressing her problems at school, her level of personal competence was that of relying on the teacher to find solutions. When dealing with life's problems was mentioned, she returned to the theme of being teased by several boys in her class. She related that the ways school helped her to solve this problem were: (a) if the teacher was watching, the teacher would tell the boys to stop; and (b) she could ignore the boys as the teacher had told her to do.

As for the presence of purposeful activity, the participant was unsure why she had to do most of the things she was asked to do at school. She responded that finding out why it was important to work on things like social studies would help her feel better about doing them, and she named mathematics as a subject that had a purpose she knew (i.e., to use in woodworking projects she engaged in with her father).

School-defined development needs.

Well-intentioned classroom procedures sometimes worked against the participant's personal development, especially in the areas of personal competence and purposeful activity.

An example of this was found in the practice of allowing her more time on her assignments. Her frustration grew as she continued to work on an assignment after the rest of the class had moved on to the next (*I'll never finish this!*). In fact, the teacher redirected her at one point when she tried to move on to the next assignment without first finishing the previous one. Her frustration became apparent when she stopped working and refused to continue, despite the prompting of the aide. At the end of the day (a Friday), she was instructed to finish all her work over the weekend as she left the classroom to go to gym.

Document-defined development needs.

An analysis of the participant's work samples from school revealed that the majority of her work was high in personal competence and skills but low in purposeful activity (all indicators of personal development). Most worksheets were also found to provide little or no evidence of autonomy, choices, or personal goals (all indicators of self-determination). Though her IEP called for abbreviated assignments, no evidence of this practice was found in the classroom. The fact that this requirement was not followed, combined with the requirement of extra time on assignments (which was followed), resulted in apparent frustration and extra homework for the participant.

Her 2nd and 3rd grade standardized test scores also revealed other participant needs. From 2nd to 3rd grade, the participant's language (84th percentile), social studies (75th percentile), and language composite (91st percentile) scores dropped markedly (to the 30th, 41st, and 44th percentiles respectively), while other scores such as spelling (90th percentile), vocabulary (68th), and science (59th) remained stable (91st, 59th, and 58th respectively). The indicated drop in language abilities and in proficiency with a subject that is heavily language laden (social studies) was a disturbing finding, especially in regard to the extensive curriculum and materials changes that occur in successive elementary grades.

Discussion

In examining the QOL framework from the viewpoint of what was most important to the participant, three broad areas of discussion emerged. The first area, *QOL overlap*, encompasses QOL dimensions and indicators discovered to be of primary importance to the participant. The second area, *dimensions not verified*, encompasses: (a) QOL dimensions and indicators that were not explicitly identified by the participant but are of seeming relevance to her and (b) QOL dimensions and indicators of seeming irrelevance to the participant. The last area, *additional indicators*, discusses the QOL indicators that were of importance to the participant but were not found in the original framework.

QOL Overlap

Four of the eight QOL dimensions from research were of primary importance to the participant: physical well-being, material well-being, rights, and social inclusion. Though every indicator in each of these dimensions was not identified as important to the participant, the ones that were identified were of sufficient emphasis and frequency to be notable.

Within the dimension of physical well-being, the participant was primarily concerned with the indicators of mobility and leisure within the school environment (as discussed above). Her optimism concerning the availability and quality of available health care made the subject a non-issue, and recreation was covered to her satisfaction by recess and other activities outside the school.

Within the dimension of material well-being, food was her primary indicator of concern. Although she indicated that she got plenty of food while at school, snack and lunch were important events in her day. Similar to health care, security was a non-issue due to positive expectations of adult care. Also, she reported two instances of not having the proper materials for an assignment (ownership), but she was content with borrowing what she needed from the teacher.

Concerning rights, she was particularly concerned with the procedures for making certain classroom decisions (voting). Decisions that concerned her most were deciding the order that students lined up for lunch and determining the permission for and frequency of student bathroom breaks, both of which were determined by the teacher. Also, she was very aware of a predictable due process for classroom discipline. In fact, her heightened sense of this process brought on declarations of her good behaviour and anxious reactions to the hypothetical prospect of *getting into trouble*.

In the area of social inclusion, indicators such as supports, work environment, and roles were all of lesser importance to the participant than acceptance, particularly in the area of peer acceptance. Teasing was a recurring theme throughout the interview, and, though on two occasions she said that she was used to the teasing, she brought up the subject whenever anything remotely connected to it was mentioned (i.e., solving life's problems).

Dimensions not Verified

Though not specifically indicated as important by the participant, there were other QOL indicators of seeming relevance to her. In light of other observation and document data, those indicators that seem to be critical for her future success were found to be purposeful activity, personal competence (both are indicators of self-determination), and friendships (interpersonal relations). Knowing the purpose and utility of an activity seemed to mediate her appreciation and attitude toward it. Also, personal competence looked to be important in building skills to help her effectively and constructively deal with teasing. Lastly, learning how to initiate and maintain a wider range of friendships was a definite need, for this could create a wider base of support in other areas as well.

QOL indicators that were not emphasized as important by the participant and were thought to be somewhat irrelevant to her included autonomy and, to some extent, choices, both being indicators

of self-determination. At her age and developmental level, autonomy is not as important an issue as it will be in the closer proximity of her teen years. Young children's range of choices, though important to provide on a smaller scale (e.g., choosing which problems or activities to complete first), are often impacted by factors outside the child's experience and maturity (e.g., choosing which school is best to attend). For the most part, major life choices are the domain of parents, though the existence of notable exceptions is definitely recognized.

Additional Indicators

QOL indicators that were of importance to the participant but were not found in the original framework were kinesthetic learning (deemed an indicator of physical well-being), social play (deemed an indicator of interpersonal relations), and academic assistance (rights).

The decision to place newly defined indicators within a particular pre-existing dimension was made in regard to the particular characteristics of the indicator and to the context within which the participant inserted the relevant information into the interview.

Kinesthetic learning emerged when the participant was asked to pick a recent school activity and tell how it made her body feel. In regard to participating in an origami lesson at school, she said, *My body felt pretty good, like I had energy*. This lesson was reiterated in two other instances in the interview.

Social play emerged from the importance the participant placed on play when deciding who were and were not her friends. In at least three instances, she defined acceptance and/or friendship by the children who consistently played with her at recess.

Academic assistance emerged as a right when she was asked about rules that help students get treated fairly. Describing a lesson on the diameter of circles, she said that, *all kids get helped by the teacher. Some get more, though, because they need more, but everybody gets helped so it's fair*.

The participant's emphasis of the importance of these indicators shows their potential impact upon her QOL at school. Not only should they be included in an examination of her QOL, but it may also be important to explore them in light of the QOL of other such children in regular education placements.

Researcher Subjectivity

The researcher's role was to establish and maintain good rapport during the participant interview yet remain as objective as possible during classroom observations and review of student records. Subjectivity awareness included an examination of the researcher's historical knowledge of the treatment of persons with disabilities, professional training and experience in special education, desire to be an advocate for persons with disabilities, and experience in evaluating teachers in classroom settings. One example of how this awareness affected the analysis of data can be found in the removal of typical age- and grade-related factors from consideration as valid QOL indicators for the participant. Indicators such as low levels of autonomy and choice in certain areas were viewed in light of appropriate operations and constraints addressing the level of development typically found in young children in elementary classrooms, instead of being considered inappropriate methods adversely affecting the participant's QOL. In addition, ethical considerations included in research methods and procedures dealt with informed consent, confidentiality, freedom of participation/non-participation, and knowledge of outcomes. Prior to data collection, the researcher explained each of these aspects to the participant and her parents, and a written form outlining these responsibilities was read and signed by the participant's parents (giving consent for the research) and by the researcher (agreeing to abide by the code of ethics).

Strengths and Limitations

The credibility of the study was strengthened by the use of data triangulation, subjectivity monitoring in observation and analysis, and the comparison of constructed realities to later checks with the participant. However, these strengths were balanced by a lack of peer debriefing

and the fact that only the participant was interviewed. Since indications of dependability rely somewhat on the establishment of credibility, and since triangulation was used, there is an argument for sufficient dependability. However, this argument is made a little less valid because stepwise replication by teams and inquiry audits were not conducted.

Similar to credibility, transferability had a balance of strengths and weaknesses. The strengths of using thick description and purposive sampling were balanced by the weakness of using only one case study, precluding the possibility of comparison. Confirmability was by far the most well established measure of trustworthiness, for assertions can be linked to the data themselves through the established trail of raw data, data reduction and analysis, process notes, and instrument development information. Though some strong methodologies were employed that strengthen the trustworthiness of the study, the limited scope accounts for the bulk of any variability in its soundness.

Implications

Social Skills Instruction

As consistent with the work of Simpson and Myles (1998) and Church, et al. (2000), there was evidence to demonstrate that in order to help the focus individual in this study achieve the highest QOL and potential for success in school, she should be the recipient of social skills instruction in applied classroom contexts (to maximize skills maintenance and generalization, among other goals). Not only could this help head off potential behaviour problems related to teasing by peers, it could also help her live a fuller life with more variety, choice, and opportunity stemming from a higher quantity and quality of guided social interaction. Also, such training could teach how to effectively communicate for the purpose of getting help in addressing unmet needs and for dealing with school-related frustrations before they build to critical levels. Social skills instruction could easily address some important QOL dimensions such as social inclusion, personal development, interpersonal relations, and self-determination.

IEP Implementation

The initial intent of IEP stipulations should be communicated and emphasized over the specific letter of the document's phrasing, with an overall focus on the holistic well being of the child. This would help ensure that classroom actions are directly connected and responsive to the ongoing needs of the child, and not merely a formality that has lost its original purpose somewhere in the details of the implementation. In addition, strict attention should be paid to treatment integrity, ensuring that all necessary modifications are being carried out as designed. This in itself would do much to help ensure the success of the child in the classroom environment. Finally, implementations of IEP provisions that place one or more of the student's critical needs in competition with each another must be sought out and resolved. Implementations that, for instance, emphasize preferential classroom placement at the expense of needed social interaction should be performed in a more complementary fashion, with planned social interactions being phased in throughout implementation of preferential placement.

Concrete Learning Approach

As in other children with developmental disabilities, children with autism spectrum disorders often have difficulty generalizing what is taught in an educational context to applicable situations in the *real world*, demonstrating a difficulty with assembling learning components into a more abstract *bigger picture* of utility and relevance (Heflin & Alberto, 2001). It is suggested by case study evidence that this is also the situation, though to a somewhat lesser degree, with the participant. Therefore, attempting to avoid a *learning for learning's sake* approach would be advisable for use with her. Concentrating instruction on how skills taught in the classroom can be used in the context of student's daily lives would provide the relevance and purpose to activities that otherwise may be viewed as meaningless and frustrating exercises, as well as provide the concrete examples often required for understanding. Though such an approach cannot be effectively used to teach every aspect of required school curricula, increasing the use of this approach could also have the potential to increase the academic success of the participant.

Conclusions

How did QOL dimensions apply to what was occurring with the participant?

Though primary participant themes did not echo the QOL framework in every aspect, this was to be expected, for QOL has been defined as an ever-evolving, individually formed perception. This does not mean, however, that QOL dimensions and their exemplary indicators were found to be of no value in examining the general education experience of a child with AD. On the contrary, they served as a viable, indicative base from which to conduct such an investigation, a base that warrants further investigation of this nature.

What did QOL indicators reveal about the appropriateness of the educational environment?

The use of QOL indicators in forming thematic interpretations revealed that the educational environment provided for the participant was, at best, mixed in its appropriateness.

Classroom supports producing positive QOL outcomes for the participant coincided with needs common to all young children (e.g., physical safety), while somewhat negative QOL outcomes often coincided with needs common to children with AD (e.g., social skills instruction). These findings further emphasize that, although children with AD have pronounced strengths, their challenges must be directly addressed so that they can be satisfied as well as ultimately successful.

Schallock (2000) underscored the need to use multiple measures of a person's perceived QOL, measures including both direct and indirect sources of data. While the present pilot study successfully employed these methods in an investigation of a child's QOL in a public school setting, they should be applied more extensively in subsequent research, perhaps by adding parent and teacher interviews and additional case examples for comparative purposes. In closing, however, it must be emphasized that QOL is a universal as well as individually applied concept, and it therefore should not be used in a misguided pursuit of a *QOL for persons with AD*.

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