POST-SCHOOL QUALITY OF LIFE OF INDIVIDUALS
WITH COMPLEX COMMUNICATION NEEDS

by

BRUCE HAMM

B.A. (English), University of British Columbia, 1991
M.A. (Critical and Cultural Theory), Cardiff University, 1994

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Name of Author (please print)  
Bruce Hamm  
Date (dd/mm/yyyy)  
04/10/2004

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Department of Educational Psychology and Counselling Psychology, and Special Education

The University of British Columbia

Vancouver, BC  Canada
Abstract

Documenting post-school outcomes is a critical step in ensuring "that schools prepare young people to live productive, satisfying lives" (British Columbia Ministry of Education, 2003). The construct of quality of life (QOL) represents a broad-based measure of post-school outcomes. Although augmentative and alternative (AAC) interventions may enhance the communication skills and educational achievements of students with complex communication needs while they are in school, there is no guarantee that these gains will be maintained following students' transition to adult life. Unfortunately, information on the post-school QOL and related outcomes of individuals with complex communication needs is scarce.

This study addressed this lack of information by examining the post-school outcomes of eight individuals with complex communication needs who used AAC in British Columbia schools and transitioned to adult life in the past 5 years. Outcomes for the participants were documented in the areas of (1) QOL, (2) important life domains (e.g., employment, education, living circumstances, etc.), and (3) communication satisfaction and modes of communication. Two surveys were used to compile the data: the Quality of Life Profile: People with Physical and Sensory Disabilities (Renwick et al., 1998) and a Communication Survey that was modeled after Slesaransky-Poe's (1997) Consumer Survey on Communicative Effectiveness but designed specifically for this study. Four of the participants and people who knew them best (e.g., family members) also participated in brief interviews in which they discussed the positive and negative aspects of their school and post-school experiences.

The results are presented in the form of individual stories designed to summarize the unique past and present experiences of each participant. While there was considerable
variation across the participants' QOL scores, their outcomes in important life domains were generally not encouraging. Participants who achieved relatively higher outcomes were distinguished on the basis of their communication satisfaction as well as indicators of communicative competence. However, the majority of participants and their supporters were very dissatisfied with the lack of services that were available to them, especially in the area of AAC. The results are discussed in relation to outcomes for adults with development disabilities in the AAC and Canadian QOL literature. Implications for future AAC research, practice, and advocacy efforts are identified.
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CHAPTER 1
Review of the Literature

In this chapter, a variety of sources pertaining to post-school outcomes for individuals with complex communication needs are reviewed. First, the Augmentative and Alternative Communication (AAC) literature is reviewed to define the nature of AAC intervention as well as challenges faced by individuals with complex communication needs. Next, literature regarding the school to adulthood transition process for individuals with developmental disabilities is considered. Here, the "traditional" post-school outcome evaluation framework is contrasted with a "quality of life" outcome framework. This leads to a review of the contemporary quality of life literature: a specific quality of life framework—developed by the University of Toronto’s Centre for Health Promotion—is discussed in detail. A number of studies documenting life outcomes of adults who use AAC are then reviewed. The chapter concludes with a discussion of the research problems and questions that arise from the relevant literatures.

Augmentative and Alternative Communication

The ability to communicate has been called the "essence of life" (United Cerebral Palsy Association, 1992, p. 5) and is commonly recognized as a cornerstone of any individual’s quality of life (QOL) (Frattali, 1998; O'Keefe, 1996). Competent communicators use a variety of expressive and receptive communication modes to interact through a variety of technological (e.g., telephones, the internet) and non-technological means (e.g., speech, gestures, body language). The term communication system refers to all of the modes of communication used by an individual. For most communicators, speech and writing constitute the core of the communication system. However, individuals described as
having *complex communication needs* are not able to rely on these modes to meet their daily communication needs. They have little or no functional speech as a result of either congenital disabilities (e.g., cerebral palsy, and intellectual disability, autism) or acquired disabilities (e.g., amyotrophic lateral sclerosis, stroke, traumatic brain injury, spinal cord injury) (Beukelman & Mirenda, 1998). In addition, without appropriate supports, individuals with complex communication needs may be forced to rely on unconventional and/or idiosyncratic verbal and non-verbal behaviours to express themselves. Their communication challenges represent a significant threat to their quality of life.

The field of augmentative and alternative communication (AAC) has developed an array of interventions and technologies specifically designed to enhance the communication of individuals with complex communication needs. The American Speech-Language-Hearing Association (ASHA) has defined an *AAC system* as “an integrated group of components, including symbols, aids, strategies, and techniques used by individuals to enhance communication” (ASHA, 1991; quoted in Beukelman & Mirenda, 1998, p. 3). In AAC interventions, individuals are supported to use techniques that *augment* their existing modes of communication (e.g., residual speech, gestures, facial expressions). For example, an individual might learn to use gestures in a symbolic manner. Such techniques are referred to as *unaided* because they utilize an individual’s existing physical capacities. Individuals may also be supplied with *alternative* modes of communication through the use of *aided* communication techniques that involve the use of “a physical object or device used to transmit or receive messages (e.g., communication book, board, chart, mechanical or electronic device, computer” (ASHA, 1991; quoted in Beukelman & Mirenda, 1998, p. 4). *High-technology* communication aids commonly include electronic or computer-based
devices equipped with communication software and synthesized voice output features. Low-technology communication aids typically include communication books or boards containing written words, symbols or pictures.

In AAC interventions, individuals are supported to use individualized combinations of aided and/or unaided communication techniques. The principal goal of such interventions is for individuals to use a communication system that enables them to participate successfully in a variety of interactions and contexts. Thus, AAC interventions involve much more than providing individuals with specific technologies. Rather, AAC interventions are dynamic in nature and involve a number of players (e.g., AAC specialists and manufacturers, service providers and school personnel, family and friends) performing a number of functions (e.g., needs assessment and resource allocation, advocacy and training, equipment maintenance and upgrading). They also require ongoing planning and evaluation, to increase the likelihood that intervention effects will be maintained as an individual transitions from one phase of life to the next (Balandin & Morgan, 2001).

The dynamic, long-term nature of AAC intervention was illustrated in Odom and Upthegrove’s (1997) case study of one AAC user’s journey to supported employment. By the age of 29, “MU” had secured part-time employment as a bank clerk despite significant physical limitations and complex communication needs resulting from athetoid cerebral palsy. The case study recounts how MU struggled to express himself at home and at school until receiving his first electronic communication device at the age of 12. Between age 12 to 29, MU received and learned to use no less than 12 different electronic communications aids and related assistive technologies. He also required specialized seating and positioning supports to facilitate access to these devices. MU graduated from high school at the age of 21.
and went on to complete a vocational program at a junior college. At age 26, the staff of a university-based employment program helped him to secure supported employment as a data entry clerk at a local bank. Odom and Upthegrove concluded that MU’s success was the result of (a) determination and perseverance on the part of himself and his family; (b) the technical knowledge and dedication of numerous agencies and service providers, and (c) a shared belief that AAC technology was not an end in itself but a means through which MU could enhance his quality of life. Clearly, one of the factors responsible for his success was the fact that his support team paid close attention to supporting his school to post-school transition so that it was both seamless and successful.

**AAC and Post-School Outcomes**

One of the most critical transitions in anyone’s life occurs when they leave school (Wehman, 2001). As one commentator noted, “school leaving…remains one of life’s decisive turning points. The kind of future we can look forward to, indeed the kind of person we will become, are very often effectively determined at this time” (May, 2001, p. 76). Post-school outcomes are determined by a number of factors, including the quality of an individual’s education, the formal and informal help an individual receives during the transition years, and the resources and opportunities an individual is able to access in the adult world (Halpern, 1993).

The case study of MU (Odom & Upthegrove, 1997) provides an example of an individual whose AAC system was maintained successfully across the school-to-adulthood life transition. But such transitions may not always go so smoothly. Balandin and Morgan (2001) observed that “times of change may be particularly distressing for augmented communicators, [as they may find themselves] in situations where their communication is not
understood and where there is little support for AAC use, update, maintenance, or repair” (p. 105). Accordingly, the transition from school to adult life may be particularly challenging for individuals who use AAC. As students, they may have received required services and supports as part of their educational programs; in the United States, for example, AAC services for students with complex communication needs are legislated under the Individuals with Disabilities Education Act (IDEA; Mirenda, 2002). Upon leaving school, however, AAC users and their families are likely to find that securing adult AAC services requires them to “navigate” through a number of government agencies and service providers (Schlosser & Rothschild, 1999). As a result, the school to adult life transition places many individuals at risk for losing the supports that were created during their school years. Loss of support, in turn, may translate to diminished communication abilities and decreased opportunities to apply the knowledge and skills they acquired in school.

Despite the importance and complexity of the school to adult life transition, we know very little about the transition experiences or post-school outcomes of individuals who use AAC (Lund, 2001). On the other hand, there is a wealth of research on the post-school outcomes of individuals with disabilities who received special education services in school.

School to Post-School Transition for Students with Disabilities

In the United States, the challenges associated with the school to adult life transition for students with disabilities are recognized in public law (Butler, in press). Legislation under IDEA has been instituted to promote continuity across students’ school and post-school accomplishments (Wehmeyer & Schalock, 2003; Wittenburg, Golden, & Fishman, 2002). Thus, planning for the transition period—defined as beginning as early as the age of 14 and continuing through to age 24—is supposed to proceed in a collaborative fashion:
Transition teams, consisting of school and adult service agency professionals, parents, and youth with disabilities, are charged with mapping out a comprehensive plan so that soon-to-graduate young adults can access the supports and services they will need to engage in a purposeful life (Cooney, 2002, p. 425).

Of course, there is no guarantee that transition legislation translates into transition practice. For example, in a study on the post-school outcomes of students with disabilities in Arizona (Love & Malian, 1997), 70% of participants reported that they had not received transition-specific support while in school. In addition, the majority of parents interviewed in the study complained that their children needed but had not received job training and placement services after leaving school. Other researchers have noted that student transitions are often hampered by confusion and/or conflict between school teams and adult service providers (Stodden, 1998; Wittenburg et al., 2002).

Perhaps these transition difficulties partly explain why many commentators in the U.S. consider post-school outcomes of former special education students to be generally disappointing (e.g., Turner, 2000; Wehman, 2001, 2002). Indeed, a large body of outcome research appears to substantiate this disappointment (e.g., Blackorby & Wagner, 1996; Wittenburg & Maag, 2002). Wehman's (2002) recent review of this research showed that, on the whole, young adults with disabilities experience chronic unemployment, rarely receive a college education, and drop out of school considerably more often than their non-disabled peers.
Quality of Life as a Post-School Outcome

Of course, achieving paid employment or obtaining a college education are not the only important post-school outcomes for youth with disabilities. In the past decade or so, researchers and commentators have sought to broaden the transition field’s conceptualizations of post-school outcomes (see Halpern, 1985, 1993, 1994; Salkever, 2000; Wehmeyer & Shwartz, 1998; Wehmeyer & Schalock, 2002). Halpern argued that an over-emphasis on employment outcomes overlooks the true spirit of the 1990 IDEA transition legislation:

Although the [IDEA] federal legislation is obviously still quite concerned with employment as an outcome of the transition process, the language is clearly framed in a broader way to acknowledge the relevance and importance of other needs and other outcomes. The term quality of life is not used explicitly in the legislation, and yet the multidimensional expression and validity of a variety of life goals are clearly implied (p. 487).

Accordingly, Halpern (1993, 1994) proposed a post-school evaluation framework focusing on QOL as expressed in three broad areas: “1. Physical and material well-being. 2. Performance of a variety of adult roles. 3. A sense of personal fulfillment” (1993, p. 490). The framework departs from previous transition models on a number of fronts. First, while it accepts that paid employment may contribute to an individual’s QOL (e.g., by enabling the person to perform valued social roles and/or enhance the person’s sense of productivity and self-esteem), it recognizes that other pursuits such as recreational, social, or spiritual activities may contribute to an equal (or even greater) extent. This claim received support from a study conducted by Halpern and associates regarding a group of students in their first
year of post-school life (Halpern, 1993). The study found that employment was not strongly correlated with QOL (Halpern, 1993). However, similar QOL research (e.g., by Schalock, Bonham, & Marchand, 2000) has contradicted Halpern’s findings.

Second, the framework’s identification of personal fulfillment as an area of concern introduces a subjective element into transition discourse. As Halpern explains, outcome evaluation involves objective and subjective dimensions: the objective dimension answers questions about an individual’s life circumstances such as “Do you have a job coach? Do you belong to a club?” The subjective dimension answers questions such as “Are you satisfied with your job coach? Are you satisfied with your time at the club?” In focusing on objective and subjective features of an individual’s transition experience, Halpern’s framework anticipates contemporary theories of person-centered QOL (e.g., Renwick et al., 2003; Schalock et al., 2002). Moreover, following Halpern’s work, QOL has been widely discussed as a post-school outcome for youth with disabilities (e.g., Love & Malian, 1997; Salkever, 2000; Wehmeyer & Schwartz, 1998; Wehmeyer & Schalock, 2001). Nonetheless, only a handful of studies have included an examination of QOL of students who received special education services while in school. For example, in their state-wide study of former special education students in Arizona, Love and Malian (1997) employed a QOL framework similar to Halpern’s. Five-hundred and twenty-eight individuals in their first year of post-school life were interviewed about the quality of their employment, their performance of adult roles, and their overall QOL. Results showed that roughly two-thirds of participants were living with their families and working in low-paying but satisfying jobs. The majority of participants said that they enjoyed a good quality of life: they reported having satisfying relationships
with family and friends, engaging in a high number of “fun activities” (p. 263), and being optimistic about the future.

Salveker’s (2000) nation-wide survey of 3,856 American individuals with disabilities between the ages of 16 and 27 (mean = 21.8 years) also examined relationships between the participants’ post-school activity status, productivity, and life satisfaction. “Activities” were defined as productive endeavours such as employment, volunteer work, housework, and educational activities. “Idleness” was defined as the absence of these activities. Overall, eighty per cent of participants reported being somewhat or very satisfied with their lives, while only 4% reported being very dissatisfied. However, more importantly, participants who reported being idle or engaging only in housework scored significantly lower on life satisfaction measures than participants involved in employment, volunteer, and/or educational activities. Unfortunately, only one-third of participants viewed themselves as being productive or very productive and about the same proportion thought they were not very productive. Salveker interpreted his findings as evidence that special education transition services should support students to become productive adults as much as employable citizens.

The picture of post-school life presented by these “QOL-oriented” studies differs considerably from the picture presented by “employment-oriented” studies reviewed by Wehman (2002). The difference can be accounted for by the fact that the latter primarily utilize objective outcome indicators (e.g., hours worked per week, monthly or annual income) while the former rely heavily on subjective indicators (e.g., satisfaction fulfillment, sense of well-being) used in conjunction with objective indicators. Indeed, subjective
evaluation constitutes the basis of contemporary person-centered QOL measurement. As Taylor and Bogdan (1990) noted:

The concept [of quality of life] has no meaning apart from what a person feels or experiences. As a corollary to the first proposition, people may experience the same circumstances differently. What enhances one person’s quality of life may detract from another’s (pp. 34-35).

In contemporary theories of QOL, the quality of an individual’s life is primarily determined by his or her personal appraisal of specific subjective (e.g., feelings, beliefs, hopes for the future) and objective aspects (e.g., housing, income, social network) of his or her life. Accordingly, the impact of work or other “universally” valued activities on an individual’s QOL will be determined by the importance the individual attributes to that work. Similarly, an individual’s satisfaction with her living circumstances may be affected by her ability to choose where and with whom she lives. An alternative way to ask the question “How good is your quality of life?” is to ask, “How good is your life for you?” (Brown, Raphael, & Renwick, 1997, p. 10).

*Measuring Quality of Life*

A number of person-centered QOL frameworks have been developed over the past twenty years; these frameworks differ in the way they operationalize and seek to measure the basic dimensions of human life and experience (Hughes & Hwang, 1996). Despite the diversity of perspectives, there is general agreement that (1) the dimensions that constitute QOL are the same for people with and without disabilities, (2) a life of quality consists of “general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential,” and (3) QOL is not a static entity: the ingredients that constitute
a life of quality for any given individual are multiple and change over time (Schalock et al., 2002, p. 458).

Given the complexity of the QOL construct, it is not surprising that researchers recommend the use of multiple methods in the assessment of QOL. Quantitative surveys generally form the basis of QOL measurement packages. A number of quantitative surveys have been developed in which respondents rate aspects of their life on 3- or 5-point Likert scales. These ratings then yield an overall QOL “score.” Examples of such surveys include the Centre for Health Promotion’s (CHP) Quality of Life Profile (Renwick et al., 1998), Schalock and Keith’s (1993) Quality of Life Questionnaire, and Cummins’ (1993) Comprehensive Quality of Life Scale. In the QOL profiles developed by the CHP, respondents rate the importance (or relevance) they ascribe to specific life domains as well as their personal satisfaction with these domains. Resultant QOL scores are thus “weighted” to reflect respondents’ unique vision of a life of quality. CHP and other researchers also gather qualitative data (i.e., through interviews and participant observation) to gain a “holistic” understanding of individuals being assessed. (Renwick & Brown, 1996; Whitney-Thomas, 1997).

The Quality of Life Project. The “Quality of Life Project” (Brown, Raphael, & Renwick, 1997) conducted by the CHP in the province of Ontario provides an excellent illustration of QOL assessment procedures. Furthermore, the study’s extensive findings represent an invaluable backdrop to outcome research conducted with adults with developmental disabilities, especially in the Canadian context. Moreover, as will be seen, the study is relevant in the context of QOL and AAC research (Lund, 2001).
In the early 1990's, the Ontario Ministry of Community and Social Services (MCSS) commissioned the CHP to conduct a province-wide assessment of the lives of adults with developmental disabilities receiving services funded by the ministry. In response, the CHP developed a quality of life model based on important "trends" in the QOL literature including the assumption that the domains that constitute QOL are essentially the same for people with and without disabilities (Brown et al., 1997). The model defined QOL as the "degree to which a person enjoys the important possibilities of his or her life" in three broad domains: Being, Belonging, and Becoming. "The Being domain includes the basic aspects of 'who one is' [including physical, psychological, and spiritual well-being]...Belonging concerns the person's fit with his/her environments [and] ...Becoming refers to the purposeful activities carried out to achieve personal goals, hopes, and wishes" (Raphael, Brown, & Renwick, 1999, p. 158). The three domains were subdivided into nine sub-domains that further operationalize aspects of a person's lived experience. The primary instrument used in the Project—The Quality of Life Profile for Individuals with Developmental Disabilities (QOLP-DD)—consisted of 54 items spanning the nine sub-domains. The Total QOL scores reported in the study represented the mean of these sub-domain scores.

Following the construction of measurement procedures, the Project assessed the QOL of 504 randomly selected adults with developmental disabilities who received MCSS-funded services in 23 areas across Ontario. Recognizing the fact that "collecting reliable data from people with developmental disabilities is sometimes challenging (p. 62)," participants' QOL was assessed from three perspectives: that of a CHP trained assessor, who completed a 27-item version of the QOLP-DD based on his or her observations and impressions of participants; the participant, who completed the QOLP-DD with the assessor's assistance;
and "an individual who knew the participant very well [and] who independently completed a 
QOLP-DD by taking the participant’s perspective" (Brown et al., 1997, p. 11). The QOLP-DD was completed by participants who “were sufficiently verbal” to do so (p. 63); 268 
participants met this criterion. The remaining 236 participants—47% of the total sample— 
were deemed “non-verbal” and received QOL scores based on the assessor’s and other 
person’s perspectives. Items on the QOLP-DD were rated on a 1 to 5 Likert-scale; scores 
were calculated using an “importance/satisfaction” weighting system and resulted in Total 
QOL scores ranging from -10 to +10. Scores above +5 indicated a “very good” QOL; scores 
between 0 and +5 indicated an “adequate” QOL, and scores below 0 indicated a “poor” QOL 
(p. 72). The Project also utilized additional measurement tools including a Personal 
Information Questionnaire to collect participant’s demographic, services, and lifestyle data 
and the Vineland Adaptive Behaviour Scales to assess levels of adaptive and independent 
functioning.

Mean scores were calculated for Total QOL and each sub-domain from all three 
perspectives. Although scores across the three perspectives varied slightly, the results 
indicated that, on the whole, “Quality of life is adequate, but not good, for people with 
developmental disabilities associated with service organizations in Ontario” (p. 126). 
Furthermore, QOL scores were generally poorer for participants who were nonverbal and had 
low functional abilities; indeed, assessor scores indicated that QOL was generally “poor” for 
nonverbal participants. Factors that were found to be associated with higher QOL scores 
generally included “living in community settings, rather than large congregate care 
[institutional] settings, having verbal skills, not having complex medical needs, and not 
taking psychotropic medications” (p. 129). Factors associated with higher QOL scores,
specifically for nonverbal participants included: “having an occupational activity of some kind; not having marked behaviour problems; having leisure activities in the community; [and] having opportunities available from which decisions can be made” (p. 129). Finally, scores in the sub-domains of Spiritual Being (“my beliefs and values”) and Growth Becoming (“things I do to grow and change”) were consistently lower than scores in the other sub-domains for both verbal and nonverbal participants from all three assessment perspectives.

The CHP drew two primary conclusions from the Project: 1) that individuals with developmental disabilities should live in small, community settings (i.e., independently, in group homes) and 2) “that ways need to be sought to increase enjoyment of life for people who are nonverbal, no matter where they live” (p. 92). The latter point has obvious implications for individuals who use AAC/have complex communication needs and serves as an appropriate segue into the topic of AAC and QOL.

**AAC and Quality of Life**

AAC can defined as both a *direct* and *indirect* “quality enhancement” technique (Schlosser, 2003). On the one hand, AAC may enhance individuals’ QOL by enabling them to make choices and directly control their environments. On the other hand, AAC may affect QOL by enabling individuals to participate in a greater number of community activities and by “opening doors” in the process. From this perspective, AAC intervention impacts an individual’s QOL directly by building competencies and indirectly by creating opportunities (Calculator, 1999).

Despite considerable discussion of the potential of AAC to enhance the lives of individuals with complex communication needs (Beukelman & Mirenda, 1998; Blackstone,
only a few studies have examined the impact of AAC on QOL. Studies by Lund (2001) and Slesaransky-Poe (1997) examined the relationship between QOL and long-term AAC use. These studies are especially pertinent to questions regarding the school-to-adult life transition for individuals who use AAC and will be reviewed in detail in the sections that follow.

*Lund (2001).* Lund's study included seven men young men (ranging from age 19 to 23) with cerebral palsy who had used AAC since preschool. All but one had participated previously in a series of studies on the communicative competence of young children who use AAC (Light 1985 a, b, c): hence, the study’s title, “Fifteen years later: Long-term outcomes for individuals who use augmentative and alternative communication.” The study is significant because it provides outcome data for a group of young long-term AAC users in important areas such as life circumstances, communicative competence, and QOL.

All of the men lived at home with their families. Josh and Anthony were in the process of completing high school; Bradley and Douglas had received “special education certificates” and were currently participating in “independent living” adult day programs. Having graduated from high school, Chad and Carson were enrolled in college programs. The latter two were the only participants who reported having vocational goals and both had previously held part-time jobs. Josh, although still in high school, worked as a motivational speaker and a part-time bank employee. Leo had dropped out of school in the tenth grade and reported spending most of his time at home.

All of the participants used multiple means of communication, including voice output communication aids (VOCAs) and a variety of unaided techniques (e.g. vocalizations, facial expressions, gestures). Three also used communication boards or books. Lund used a
number of standardized instruments to assess the participants' expressive communication abilities (e.g., the Functional Assessment of Communication Skills for Adults; Frattali, et al., 1995). Not surprisingly, the assessments showed that, since the 1985 preschool studies, the participants' abilities had improved in areas such as linguistic complexity and conversation skills. On the other hand, the participants generally demonstrated limited improvement in their range of communicative functions and expressive spontaneity: for example, they rarely asked questions, often relied on their communication partners to initiate communicative exchanges, and favoured responding to yes/no rather than open-ended questions. The participants' receptive language abilities and literacy skills were also assessed. Lund noted that the group's receptive scores were generally poor. Indeed, the three participants who achieved the highest scores on the Peabody Picture Vocabulary Test-Revised (PPVT-R)—Chad, Josh, and Carson—scored more than 1.5 standard deviations below the standardized mean, which was “significantly below their same-aged non-disabled peers” (Lund, p. 62). Reading comprehension tests showed that the “participants were not independently reading at a level sufficient for high school and college material” (p. 122). Despite the fact that Chad, Carson, and Josh attained appreciably higher scores than the remaining four participants, the assessments conducted by Lund indicate that the participants' communication capacities were generally compromised when compared to the general population.

QOL assessment was conducted using the CHP's Quality of Life Profile: People with Physical and Sensory Disabilities (Renwick, et al., 1998). The instrument yields QOL scores that range from -10 to +10. Scores in the range of +5 to +10 indicate a “very good” QOL, scores in the range of 0 to +5 indicate an “adequate” QOL, and scores below 0 indicate a “poor” QOL (Brown, Raphael, & Renwick, 1997). All of the participants in Lund's study
achieved QOL scores above 0. Although Lund does not explicitly identify links between the participants’ QOL scores, communicative competence scores, and life circumstances, noteworthy relationships between the data sets can be gleaned from the text. Specifically, it is significant that the Chad and Carson, the only participants to receive QOL scores in the “very good” range (8.0 and 7.1, respectively) were two of the three participants to be distinguished on the basis of both communication outcomes (i.e., obtaining considerably higher expressive and receptive assessment scores than other participants) and life achievements (i.e., graduating from high school, attending college). Along similar lines, Josh, the third participant to be distinguished in the areas of communication and life achievement outcomes (i.e., also obtaining high assessment scores, working in a bank and as a motivational speaker) achieved a QOL score (4.5) just below the “very good” range. On the other hand, Bradley, and Douglas, who achieved some of the lowest communication assessment scores and were attending adult day programs achieved QOL scores of 3.5 and 1.8, respectively. Similarly, Anthony, who had also achieved low communication scores (and was still in high school), achieved one of the lower QOL score in the group (3.5). These findings indicate a strong correlation between the communication capacity, life achievements, and QOL scores of the participants in Lund’s study.

Finally, the interview portion of Lund’s study yielded a number of qualitative themes regarding the “contextual factors” affecting the participant’s lives. The participants and their family member identified specific barriers to communicative competence and quality of life including difficulties obtaining services to repair and/or maintain AAC technologies, failure on the part of service providers to truly understand the needs of individuals with complex communication needs, and a lack of collaboration between intervention team members.
Supports included the participants’ sense of being included in their community, the efforts of family members and service providers in sustaining AAC access, and the participants’ strengths and positive attitudes.

In all, Lund’s study provides evidence that (1) it is possible for individuals with complex communication needs to sustain AAC interventions across the school-to-adult life transition, (2) that individuals who use AAC can achieve important life outcomes (e.g., in vocational and educational domains) and obtain positive and even strong QOL scores, even in the face of relatively limited communication abilities, and (3) research may uncover correlations between the communicative competence, life achievements, and QOL scores. Slesaransky-Poe (1997). Slesaransky-Poe’s (1997) study contributes important insights regarding the relationship between AAC use, communication satisfaction, and QOL with a sample of AAC users that is not only larger but more heterogeneous than Lund’s. The study, conducted “to assess whether the use of voice output communication devices [VOCAs] makes a difference in the communicative effectiveness and the QOL of adults with significant speech disabilities” (p. 54) included 65 individuals with complex communication needs, 45 who used VOCAs (herein termed the “VOCA group”) and 20 who did not (the “non-VOCA group”).

According to Slesaransky-Poe, the VOCA and non-VOCA groups were essentially matched in terms of demographic data. Most of the participants were in their 30’s and 40’s and had at least 12 years of formal education. About half lived in their own homes or apartments and roughly 40% lived with their families; the remainder resided in “community living” arrangements. Just over 40% of the participants were employed on a full- or part-time basis while; the remainder were involved in either formal education or held volunteer
positions (16%), attended adult day programs (18%), or spent their days at home (20%). As for disabilities, approximately 90% of the VOCA group and 50% of the non-VOCA group had cerebral palsy. The remaining participants reported suffering from brain injury or stroke, while three members of the non-VOCA group had mental retardation and/or autism. Participants from both groups reported using a variety of unaided means to communicate; interestingly, only three members of the non-VOCA group used communication boards or books. Ninety percent of the VOCA group felt that they effectively communicated using their VOCAs.

Participants completed the *Consumer Survey on Communicative Effectiveness* (Slesaransky-Poe, 1996), which asked them to rate their satisfaction with their communication, independence, productivity, and community inclusion. Based on the findings of a t-test for independent samples, communication satisfaction ratings were significantly higher for the VOCA group than for the non-VOCA group. Specifically, over 85% of the VOCA group reported that they were satisfied or very satisfied with their overall communication when using their devices. On the other hand, only 35% of the non-VOCA group reported being satisfied or very satisfied with their overall communication abilities. The VOCA group also reported being significantly more satisfied with their communication when using their VOCA compared to their communication when not using their VOCA. Notable divergences between the two groups' scores were evident in other important areas of the survey. For example, the majority of VOCA users felt that their use of the communication device promoted their independence, productivity, and inclusion in the community. Conversely, only one-third of the non-VOCA group rated themselves as being “very independent” while another third simply deemed themselves to be “not independent.”
Similarly, one-third said they were included or very included in the community while half said they were only somewhat included. The group’s productivity scores were generally more positive with more than 50% reporting that they believed themselves to be productive or very productive. On the whole, results from the Consumer Survey on Communicative Effectiveness were much more favourable for the VOCA group.

Both groups also completed Schalock and Keith’s (1993) *Quality of Life Questionnaire*. Designed primarily for use with individuals with mental retardation and related developmental disabilities, the *Questionnaire* measures QOL as expressed in terms of independence, productivity, community inclusion, and general satisfaction. Mean scores from the *Questionnaire* indicated that (1) members of both groups generally enjoyed a good QOL and (2) QOL scores for VOCA group were slightly higher than QOL scores for the non-VOCA group. However, t-tests indicated that the difference between the two groups was not statistically significant. Consequently, despite showing a positive relationship between VOCA use and communication satisfaction, Slesaransky-Poe’s hypothesis that individuals with complex communication needs who use a VOCA will achieve higher QOL scores than similar individuals who do not use a VOCA was disconfirmed. Overall, this study provides mixed evidence regarding relationships between communication satisfaction, QOL, and VOCA use. On the other hand, it presents a needed picture of the diverse outcomes for and life circumstances of individuals with complex communication needs and provides an important base for further AAC inquiry.

*Additional QOL studies.* The health-related well-being/QOL of individuals who use AAC has received cursory examination in only a few other studies. Tolley and colleagues (1995) measured the impact of AAC interventions on 127 individuals with speech impairments in
the United Kingdom. After using communication aids for approximately 3 months, participants completed a modified version of the *Rosser Classification of Disability/Distress Ratings* (Kind, Rosser, & Williams, 1982) and/or provided a brief self-rating of their QOL. The *Rosser* is designed to measure the impact of an individual’s disability on his or her life. Thirty-eight percent of the 78 participants who completed the *Rosser* indicated a positive gain in their disability/distress ratings following AAC intervention; there was no change in ratings for the remainder of participants. Of the 99 participants who rated their post-AAC intervention QOL, 32% said that their life was “much better,” 54% said that their life was “slightly better,” and 23% indicated that their life had not changed.

Haas and colleagues studied the impact of “computer-aided assistive technology” (CAAT) on the goal fulfillment and *health-related* QOL of 74 individuals with communication disabilities in Sweden. Participants completed a goal fulfillment rating scale and a version of the *Nottingham Health Profile* (Wiklund, 1992) prior to receiving CAAT and 3 years afterwards. The *Profile* assesses an individual’s health-related well-being on the basis of his or her social isolation, pain levels, sleep patterns, and physical energy. Results indicated that participants made gains in terms of goal fulfillment ratings but not in health-related QOL ratings following 3 years of CAAT intervention.

Although the four studies just reviewed may be too methodologically different to compare, the findings of each suggest that the nature of the relationship between AAC use and QOL is still elusive and that the former does not guarantee increases in the latter.

*Survey research on important life domains.* A number of surveys have been conducted to explore the variety of life circumstances of individuals who use AAC. These surveys are important because, on the one hand, they provide evidence that it is possible for individuals
who use AAC to achieve desirable life outcomes (e.g., Huer, 1991; McNaughton, Light & Groszyk, 2001; Odom & Upthegrove, 1997) but, on the other hand, illustrate some of the challenges faced by such individuals who use AAC (Balandin & Morgan, 2001; Murphy et al., 1995). On the whole, these studies provide a sense of the range of possible futures faced by young individuals with complex communication needs.

In regard to challenges faced by individuals with AAC, Balandin and Morgan (2001) explored the aging process of individuals with cerebral palsy who use AAC. Their study included 78 individuals between the ages of 30 to 69 living throughout Australia. The researchers found a number of factors related to the aging process which posed a threat to the independence and quality of life of the participants. For example, the fact that only 22% of participants were employed and only 15% owned their own home meant that they lacked the resources necessary to dictate the kind of care they would receive later in life. Furthermore, most of the participants reported a limited capacity and willingness to communicate with health professionals and service providers about their changing needs. The latter problem was exacerbated by the fact that many of the participants had limited access to a natural advocacy network (i.e., of family and friends). The authors feared that, on the whole, the participants lacked the resources necessary to maintain their communication abilities and thus successfully manage the aging process—they called for further research into the kinds of knowledge and supports needed to maintain the “voice” of individuals who use AAC as they proceed through life (p. 107).

While Balandin and Morgan’s study highlighted the challenges faced by individuals who were at risk for losing some or all of their capacity to communicate, a demographic study by Murphy and colleagues (Murphy, Markova, Moodie, Scott, & Boa, 1995)
documented the life circumstances of Scottish individuals with complex communication needs who had recently embarked on the process of AAC intervention. The study was conducted in response to "a significant increase in the use of AAC systems [in Scotland] over the last 3 years" (p. 26). Using a mail survey, the authors obtained demographic information for 216 individuals with cerebral palsy, 107 of whom were adults (i.e., over the age of 20). At the time of the study, approximately 80% of the participants had used a high- and/or low-technology communication aid for three years or less (149 used some type of high-technology aid; 142 used some type of low-technology aid). Data collected regarding the participants' use of their aids—e.g., the fact that over 20% of the participants used their aids solely in therapy contexts—prompted Murphy and colleagues' conclusion that "it appears that very few, if any, [AAC] users have reached their communication potential" (p. 32). Moreover, the researchers found little evidence to suggest that the use of communication aids had enabled the participants to be part of integrated, community settings. For example, almost half of the adult participants reported living in their "Own/Family home" while the other half lived in group homes or care facilities (e.g., hospitals, p. 29). Furthermore, only one participant was enrolled in full-time higher education and none were gainfully employed—the majority of adults attended "special and segregated day placements" (p. 32). On the basis of these generally discouraging findings, the researchers called for further provision of AAC services in Scotland with an emphasis of supporting individuals who use AAC to communicate in personally meaningful, community-based contexts.

Naturally, follow-up data to the studies by Murphy and colleagues and Balandin and Morgan would have provided invaluable insights into the possibilities of sustaining AAC interventions as well as the potential benefits of sustained AAC use. As mentioned earlier,
however, a small body of U.S. research has stressed the importance of looking past the hardships experienced by individuals with complex communication needs to the achievements of individuals who use AAC. Generally speaking, the goal of such research is to change the light in which individuals who use AAC are viewed, to help these individuals “cast off the cloak of incompetence” and thus be embraced as valuable members of their communities (Bryden, Slesaransky, & Baker, 1995, p. 79).

Within research looking at the achievements of individuals who use AAC, three studies conducted by McNaughton and colleagues (Light, Stoltz, & McNaughton, 1996; McNaughton, Light, & Groszyk, 2001; McNaughton, Light, & Arnold, 2002) are notable not only for examining individuals’ vocational achievements but also for exploring some of the conditions associated with those achievements. These studies collected the perspectives of individuals with a variety of disabilities via mail surveys and/or on-line discussion groups. Specifically, Light and colleagues (1996) conducted a study with 25 participants ranging in age from 22 to 56 years. Seventy-six percent of the participants had cerebral palsy; the remaining participants reported having autism and/or intellectual disability. Almost half of the participants worked as clerks or labourers—the other half held a variety “white collar” or service-based positions (e.g., AAC educator/advocate, counsellor). None of the participants worked on a full-time basis. On the other hand, the eight participants in McNaughton and colleagues’ (2001) study reported working upwards of 40 hours per week and being "financially independent" as a result of their jobs (as, for example, teachers, researchers, and AAC advocates and educators). The fact that all of the participants in this study had cerebral palsy (without intellectual challenges) may have represented an important variable (relatively speaking) in these individuals’ achievements. In contrast, the six participants with autism
and/or intellectual disabilities in Light’s study worked as either part-time labourers or clerks. Disability issues of a slightly different nature were raised in McNaughton and colleagues’ (2002) study of five individuals with amyotrophic lateral sclerosis (ALS) who used AAC. The onset of ALS—a degenerative neurological disorder that may affect, among other things, an individual’s communication abilities—threatens an individual’s capacity to maintain the employment status that he has enjoyed throughout his adult life. McNaughton and colleagues’ study thus provided valuable evidence that AAC intervention can help individuals remain in the workforce following the onset of the disorder. Although most of the participants carried reduced workloads, each managed to maintain their original positions (i.e., as a pharmacist, a school administrator, a corporate contract negotiator, an account director, and a magazine editor/writer). The participants reported that AAC intervention enabled them to maintain much of their independence, sense of self-worth, and quality of life.

Despite differences in their disability types, ages, and backgrounds, participants in the three studies identified a remarkably similar range of supports and barriers to employment. Supports included personal characteristics (e.g., determination, time management skills), positive educational experiences, government programs and policies, and the assistance of family members and co-workers. Not surprisingly, access to assistive technologies and services was also identified as a support. Indeed, most of the participants in the studies used a combination of high-technology, low-technology, and unaided AAC. The majority of white collar workers used computer-based technologies for purposes of written output. Moreover, as testament to the power of sustained intervention, many of the participants in the 1996 and 2001 studies reported using some of their assistive and communication technologies for a
minimum of six years. On the other hand, barriers to employment included negative attitudes of others in the workplace, lack of appropriate education, technological difficulties (e.g., lack of support to maintain or fix assistive technology), and misunderstandings with co-workers (often caused by the slowness of assistive devices). One of the caveats to these employment success stories was the fact that a large number of the participants in the 1996 and 2001 studies worked for “agencies involved in disability-related services” (Light, Stoltz, & McNaughton, p. 221). The researchers argued that these outcomes reflected the limited employment options for individuals who use AAC. Generally speaking, however, the vast majority of participants reported being satisfied with their job duties, their supervisors and co-workers, and their salaries.

As for education, roughly half of the participants had graduated from high school and/or college—indeed, a total of six participants in the 1996 and 2001 studies had obtained graduate degrees. The studies thus demonstrate that it is possible for individuals who use AAC to obtain employment as well as receive post-secondary education. And, although the studies demonstrate the potential benefits of education for individuals who use AAC, little is known about the post-secondary educational experiences of such individuals. Research by Huer (1991) represents the sole exception here. In her survey, Huer randomly selected American universities to obtain demographic data in areas such as the typical ages of university students using AAC, disability types, and the number and types of campus services available to them. Results of the study showed that, in 1988, “there were approximately 127 AAC consumers identified across 98 university programs sampled” (p. 236). The most common diagnoses of students reported to use AAC were cerebral palsy, multiple sclerosis, closed head injury, and muscular dystrophy. Huer was surprised to find
that “AAC consumers are enrolling in higher education at approximately the same ages as able-bodied students [i.e., starting at 18 years of age and up]” (p. 233). While this study provides little insight regarding conditions that promote post-secondary achievements of individuals who use AAC, it is important because, like the studies by McNaughton and colleagues, it shows that the use of AAC can have a powerful impact on the life outcomes of individuals with complex communication needs.

Summary

A number of important themes emerge from the foregoing review of the literature. Specifically, the AAC literature suggests that AAC intervention can promote large and small achievements by individuals with complex communication needs. However, it is also evident that the use of a specific communication technologies do not result in a “quick fix” nor do they guarantee the attainment of a certain standard of quality of life. Instead, valued outcomes appear to require the ongoing development and implementation of interventions that are carefully planned and evaluated. A similar emphasis on planning and preparation subtends U.S. policies on the transition from school to adulthood. Unfortunately, much of the literature indicates that life beyond the classroom may not be particularly bright for individuals with developmental disabilities in domains such as employment and post-secondary education. On the other hand, advocates of a quality of life approach to outcome evaluation have argued that post-school life is too complex a phenomenon to be measured by achievements in the areas of work or education. And while researchers such as those from the CHP have developed a suitably complex, multi-faceted quality of life assessment tool, applications of the tool have not found particularly favourable outcomes for individuals with developmental disabilities living in Canada. Moreover, Canadian educational systems have
not legislated proactive transition procedures into their practices as the U.S. system has (although it appears that the effects of these legislations on outcomes is negligible). On the whole, then, it appears that the “deck is stacked” against young Canadians with complex communication needs and there is much to be learned about their predicament.

**Research Problem**

Documenting post-school outcomes is a critical step in ensuring “that schools prepare young people to live productive, satisfying lives” (British Columbia Ministry of Education, 2003). Unfortunately, little is known about the post-school outcomes of individuals with complex communication needs living in Canada (let alone the province of British Columbia). For example, we know little about these individuals’ experiences and achievements during their first few years out of school. We also know little about their communication lives after graduation: are they able to continue to use the AAC systems that were provided to them in school? If not, how do they communicate and what are the ramifications for their lives?

Without answers to these questions, we lack an empirical base upon which to evaluate the long-term impact of the services and supports that Canadians and British Columbians with complex communication needs receive as students or as young adults.

This research addressed this lack of information by examining the post-school outcomes of individuals with complex communication needs who used AAC in British Columbia schools and transitioned to adult life in the past 5 years. Fortunately, the existent outcome literature for individuals with complex communication needs—although predominantly of U.S. origin—provided a framework from which to begin the process of documenting these outcomes (as reviewed above). Accordingly, outcomes were documented in the areas of QOL and important life domains (e.g., employment, education, living
circumstances, etc.). Participants were also asked to provide information about the means by which they currently communicate and to rate their satisfaction with their current communication abilities. Two surveys were used to compile these data: the Quality of Life Profile: People with Physical and Sensory Disabilities (Renwick et al., 1998) and The Communication Survey modeled after Slesaransky-Poe’s (1997) Consumer Survey on Communicative Effectiveness but designed specifically for this study. Finally, participants were asked to participate in brief interviews which afforded them an opportunity to talk about the positive and negative aspects of their school and post-school experiences. The specific questions addressed in this study were as follows:

- What were the school experiences of the participants with complex communication needs in the study, as measured by the Communication Survey and interviews?

- What are the post-school outcomes for individuals with complex communication needs in the important life domains of education, employment, living circumstances, and recreational activities as measured by the Communication Survey and interviews?

- What is the quality of life for these individuals as measured by the QOLP-PD? Is there an apparent relationship between each person’s QOLP-PD scores and their educational, vocational, recreational, and living circumstances outcomes?

- What modes of communication are currently used by individuals with complex communication needs who participated in the study, and how many continue to use the communication technologies (or comparable communication technologies) they received in school? Furthermore, how satisfied are these individuals with their ability to communicate for a variety of purposes and in a variety of contexts as measured by the Communication Survey and interviews?
CHAPTER 2

Methods

Participant Recruitment

Individuals were eligible for participation in the study on the basis that they: (1) were under the age of 25; (2) left, graduated from, or dropped out of a British Columbia high school between 1998 and 2003; and (3) received communication technology (e.g., an IntroTalker, a Big Mack) from Special Education Technology-British Columbia (SET-BC) (a B.C. Ministry of Education provincial resource program) while attending high school. As of July 2003, SET-BC’s database indicated that 79 individuals met the criteria outlined above. In the summer of 2003, SET-BC attempted to contact these individuals by telephone, to confirm their current mailing addresses and inquire about their willingness to participate in this study. SET-BC was not able to contact 44 of these individuals for one of the following reasons: (1) the telephone number in SET-BC’s database was no longer in service; (2) the SET-BC caller left a message for the individual to contact SET-BC but this did not occur; (3) the SET-BC caller reached a party at the database telephone number but was informed that the individual had never lived at that residence; (4) the SET-BC caller reached a party at the database telephone number but was informed that the individual had moved away and his or her whereabouts was unknown. In addition, two individuals were deceased and three who were contacted declined to participate in the study because they were not interested. A total of 30 individuals (and/or their guardians) agreed to participate in the study by receiving a survey package.
Survey Distribution and Returns

The 30 potential participants were sent a survey package containing a cover letter explaining the nature of the study (Appendix A), a consent form (Appendix B), a lottery entry form (Appendix C), and two surveys: the Communication Survey (Appendix D) and the Quality of Life Profile: People with Sensory and Physical Disabilities (QOLP-PD, Renwick, Rudman, Raphael, & Brown, 1998) (Appendix E). The cover letter asked potential participants to return the surveys in a self-addressed, stamped envelope within 3 weeks. Follow-up reminder postcards were mailed to potential participants 21 days after the initial mailing (Appendix F). Completed survey packages were returned by the guardians of eight participants (incomplete and therefore unusable survey packages were returned by the guardians of three additional individuals). The return rate was 27%. Due to the nature of their disabilities, none of the participants were able to give consent to participate in the study on their own behalf. Instead, their legal guardians provided consent (in each case, a parent). The names of the eight participants were entered into a lottery for a $100 gift certificate to a local restaurant or bookstore—the lottery was intended to encourage individuals to complete and return the survey materials (see Appendix C). The lottery occurred after the final cutoff date for survey returns and the prize was sent to the winning participant at that time.

The consent form asked participants and/or their guardians if, in addition to completing the survey materials, they would be willing to participate in a brief interview regarding the participant’s communication, school and post-school experiences. The parents of four participants agreed to be interviewed with their son or daughter—these interviews were conducted with participants and their families between December 2003 and May 2004.
Participants

The demographic characteristics of the participants are summarized in Table 2.1. All participant names are pseudonyms.

Table 2.1

Participants' Demographic Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (Year: month)</th>
<th>Gender</th>
<th>Language at home</th>
<th>Region in BC</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>24:9</td>
<td>F</td>
<td>English</td>
<td>Lower Mainland</td>
<td>autism, intellectual disability</td>
</tr>
<tr>
<td>Cindy</td>
<td>21:7</td>
<td>F</td>
<td>English</td>
<td>Lower Mainland</td>
<td>cerebral palsy, intellectual disability</td>
</tr>
<tr>
<td>Dianne</td>
<td>22:10</td>
<td>F</td>
<td>English</td>
<td>Lower Mainland</td>
<td>Rett Syndrome</td>
</tr>
<tr>
<td>Jason</td>
<td>19:9</td>
<td>M</td>
<td>Cantonese, English</td>
<td>Lower Mainland</td>
<td>autism, cerebral palsy, intellectual disability</td>
</tr>
<tr>
<td>Jeremy</td>
<td>22:10</td>
<td>M</td>
<td>English</td>
<td>Lower Mainland</td>
<td>cerebral palsy</td>
</tr>
<tr>
<td>Kerry</td>
<td>24:1</td>
<td>F</td>
<td>English</td>
<td>Okanagan</td>
<td>cerebral palsy</td>
</tr>
<tr>
<td>Naomi</td>
<td>23:11</td>
<td>F</td>
<td>English</td>
<td>Vancouver Island</td>
<td>intellectual disability</td>
</tr>
<tr>
<td>Ursula</td>
<td>22:9</td>
<td>F</td>
<td>English</td>
<td>Sunshine Coast</td>
<td>cerebral palsy, deafblindness, intellectual disability</td>
</tr>
</tbody>
</table>
As the table shows, the participants ranged in age from 19 years 9 months (Jason) to 24 years 9 months (Amy). The mean age of the participants was 22 years 8 months. The group consisted of six women—Amy, Cindy, Dianne, Kerry, Naomi, and Ursula—and two men, Jason and Jeremy. Only Jason’s family spoke a primary language other than English at home: his mother reported that the family spoke both English and Cantonese. The majority of the participants lived in the Lower Mainland (i.e., 5 of 8) with Kerry (Okanagan), Jeremy (Vancouver Island) and Ursula (Sunshine Coast) hailing from other regions of the province. Finally, the participants reported a variety of disabilities: four had cerebral palsy (Cindy, Jeremy, Kerry, and Ursula), two had autism (Amy and Jason), one had Rett Syndrome (Dianne), and one had an intellectual disability with no other diagnosis (Naomi). Amy, Cindy, Jason, and Ursula had an intellectual disability in addition to their primary diagnoses, and Ursula also had severe vision and hearing impairments.

**Instruments/Data Collection**

Eight participants completed two surveys: the *Communication Survey* and the *QOLP-PD*; four participants also participated in brief structured interviews.

*Communication Survey.* (Appendix D). The *Communication Survey* was developed specifically for the research study. It consisted of three sections: (1) *Information About Yourself*, (2) *Your Communication*, and (3) *Survey Help*. The survey was modeled on the *Consumer Survey on Communication Effectiveness* (Slesaransky-Poe, 1995) and the *QOLP-PD* (Renwick et al., 1998).

In the first section, *Information About Yourself*, participants completed a series of yes/no and multiple choice questions regarding their personal characteristics (i.e., age, gender, etc.); living circumstances; support needs; and the vocational, educational, and
recreational activities in which they participated at the time of the survey. They also provided information regarding their past and current communication modes and whether they continued to use the communication device (or a comparable device) that they received from SET-BC when they were in school.

In the second section, *Your Communication*, participants responded to 27 items corresponding to three communication areas: Communication with People, (e.g., friends and family, service providers), Communication in specific Places (e.g., at work, at home), and Communicative Functions (e.g., communicating for wants and needs, social closeness, etc.). Participants first rated the *Importance* they accorded to each item on a 5-point Likert scale (i.e., 1 = not at all important; 5 = extremely important). They then rated their personal *Satisfaction* with each item, also on a 5-point Likert scale (i.e., 1 = not at all satisfied; 5 = extremely satisfied). Participants were instructed to respond “Don’t Know” to items they were uncertain about or “Not Applicable” to items they deemed irrelevant. Items coded “Don’t Know” or “Not Applicable” were not included in the calculations of communication scores.

Scores from the *Your Communication* section were calculated in the following manner: (1) Importance and Satisfaction ratings for each item in a given communication area were totaled and divided by the valid *n* (i.e., the number of items completed by a participant in that area), resulting in overall Importance and Satisfaction scores for that area. (2) The Importance and Satisfaction scores for each communication area were each added and divided by three, producing a Total Communication Importance score and a Total Communication Satisfaction score. The difference between an individual’s Importance score and Satisfaction scores in a given communication area represents the gap or discrepancy
between that individual's *hopes* or *expectations* for her communication in that area and her satisfaction with her *actual* communication in that area. In all, the *Your Communication* section provided a means to ask each participant in the study (to paraphrase the *QOLP-PD* manual, p. 1), "How good is your communication for you?"

In the final section, *Survey Help*, the participants reported the type and amount of support they required to complete the surveys. Due to their disabilities, six of the participants were not able to complete the surveys; in each case, their mothers completed the surveys on their behalf (i.e., by answering the items from the son or daughters' *perspective*). Cindy and Kerry required some support from their mothers to complete the surveys (e.g., assistance to record answers).

**Quality of Life Profile: People with Physical and Sensory Disabilities.** Participants' quality of life was measured using the *QOLP-PD*. The *QOLP-PD*, rooted in the CHP's QOL framework, is comprised of three general life domains—Being, Belonging, and Becoming—and nine sub-domains. The instrument was constructed with "the underlying assumption that quality of life issues are the same for people with and without disabilities, although adults living with chronic physical disabilities may address those issues somewhat differently during the course of their daily lives" (Renwick et al., 2003, p. 163). The items on the *QOLP-PD* were developed and refined in concert with individuals with a variety of physical disabilities, a process which, according to the authors, contributes to the instrument’s face and content validity. It received further validation in the course of a study with adults with physical disabilities living in Ontario \( n = 27 \) and Saskatchewan \( n = 40 \). The instrument’s construct validity was evaluated by calculating correlations between both group’s mean sub-domain scores and Total QOL scores (adjusted to exclude measured sub-domain scores).
Moderate to high correlations were found, indicating that “the items in each [sub-domain] tap into the overall concept of quality of life but no single [sub-domain] score completely captures the overall construct” (p. 177). Reliability tests for the instrument yielded alpha coefficients ranging from 0.67 to 0.97 in the Ontario sample and 0.84 to 0.98 in the Saskatchewan sample. The authors concluded that psychometric properties of the QOLP-PD were generally sound but recommended further validation research with larger samples. They discussed a number of the instrument’s positive features highlighted during the study, including the fact that it can be self-administered (as it was in the Saskatchewan group) and that it is “applicable for use across people with a wide range of disabilities, including multiple disabilities” (p. 179). The QOLP-PD was chosen for use in this study to facilitate comparison with research concerning individuals with complex communication needs and physical and/or developmental disabilities who also completed the QOLP-PD (i.e., Lund, 2001) or a similar CHP QOL instrument (i.e., Brown, Raphael, & Renwick, 1997).

The QOLP-PD consists of 102 items across three sections pertaining to the areas of Being, Belonging, and Becoming. The Being area is further divided into the sub-areas of Physical Being (“my body and my health”), Psychological Being (“my thoughts and feelings”), and Spiritual Being (“my beliefs and values”). The Belonging area is divided into the sub-areas of Physical Belonging (“where I live and spend my time”), Social Belonging (“the people around me”), and Community Belonging (“my access to resources”). Finally, the Becoming area is divided into Practical Becoming (“the daily things I do”), Leisure Becoming (“the things I do for fun and enjoyment”) and Growth Becoming (“The things I do to improve myself”). Total QOL scores on the QOLP-PD represent the mean score of the
nine sub-areas just listed. Scores from the *QOLP-PD* are reported on a 21-point scale ranging in value from a high of +10 to a low of -10 (scoring procedures are explained below).

The participants (or their parents) rated each item on the *QOLP-PD* on a 5-point Likert scale, first to indicate the importance they accorded each item (i.e., 1 = Not at all important, 5 = Extremely important) and then to indicate their personal satisfaction with each item (i.e., 1 = Not at all satisfied, 5 = Extremely satisfied”). As in *The Communication Survey*, participants were instructed to respond “Don’t Know” to items they were uncertain about or “Not Applicable” to items they deemed irrelevant. Items coded “Don’t Know” or “Not Applicable” were not factored into sub-area scores.

Calculation of the participants’ *QOLP-PD* scores began with the conversion of Importance and Satisfaction scores from each item into “Basic” scores for each sub-area in the following manner (Renwick et al., 1998, 2003): First, Importance and Satisfaction scores for the items in each sub-area were totaled and divided by the valid *n*, yielding mean Importance and mean Satisfaction sub-area scores; then, 3.00 points were subtracted from each total Satisfaction score, and the resultant number was multiplied by the sub-area total Importance score. To illustrate this procedure, a raw total Satisfaction score of 4.50 and a total Importance score of 4.00 would be converted into a Basic score as follows: 4.50 - 3.00 = 1.50 (adjusted Satisfaction score), 1.50 × 4.00 = 6.00 (Basic Score). The procedure yielded Basic scores that were “weighted” to reflect the degree of importance (lesser or greater) participants accorded each *QOLP-PD* item (i.e., items accorded higher importance scores had greater positive or negative influence on participants’ *QOLP-PD* scores than did lower importance scores). This weighting system represents one of the ways that personal preferences and values are factored into the *QOLP-PD*’s measurement of QOL. Scores on the
QOLP-PD above 5 indicate a "very good" QOL that should be "maintained and expanded," scores between 0 to +5 indicate an "adequate" QOL that should be "improved and expanded," and scores below 0 indicate a "strong need to improve quality of life" (Brown, Raphael, & Renwick, 1997; Renwick et al., 1998).

The instrument concludes with a series of items that are not factored into the final quality of life score. In Decision Making, respondents rate the amount of control they have over important areas of their lives; and in Potential Opportunities, respondents rate the amount of alternatives or choices that are available to them in specific areas of their lives. The QOLP-PD manual recommends that results from these sections be considered during the interpretation of respondents' overall quality of life scores.

Interviews. CHP and other researchers (e.g., Whitney-Thomas, 1997; Schalock et al., 2002) have argued that naturalistic methods constitute an integral part of QOL measurement because "the use of open-ended approaches focuses primarily upon the processes of the topic of interest—quality of life of persons with developmental disabilities—and allows for the uniqueness of individuals to emerge" (Woodill, Renwick, Brown, & Raphael, 1994, p. 65). Accordingly, the study included interviews that afforded participants the opportunity to discuss their school careers, post-school quality of life, and communication "in their own words." The researcher conducted brief (approximately 1 hour) structured interviews in the family homes of four participants. Interview questions concerned (a) the positive and negative aspects of the participants' school careers, (b) the factors that contributed to and detracted from the quality of their school experiences, (c) the positive and negative aspects of their present lives, (d) the factors that contributed to and detracted from their current quality of life, (e) things that could be done or could have been done to alter present
or previous negative experiences, and (f) aspects of their past and current communication life that were not captured in the *Communication Survey*. A generic interview protocol is included in Appendix G.

Due to their disabilities and communication challenges, the participants responded to interview questions to varying degrees. Although the majority of information collected during the interviews was provided by family members and, in one case, by a paid support worker, the greatest care was taken to capture the participant’s perspectives and “voice.” The following procedures were employed with this goal in mind. First, questions were initially posed to the participants. If the participant responded to the question, the interviewer decided whether he should (1) check his understanding of the participant’s response with the family member/support worker, or (2) ask the family member/support worker to elaborate on the participant’s response (e.g., to provide more details regarding specific aspects of the participant’s life or communication). If the participant did not respond to the question, the interviewer solicited assistance of family members/support worker to re-phrase the question in a way that was easier for the participant to understand and/or respond to (e.g., re-phrasing an open-ended question in yes/no form). If the participant responded to the re-phrased question, the interviewer again decided whether to check for clarification and/or request for an elaboration. If the participant did not respond to the re-phrased question, the family member/support worker was asked to do the best he or she could to answer the original question *from the participant’s perspective*.

The interviews were video- and audio-taped and transcribed. The verbal and non-verbal responses of the participants and their family members were transcribed following the notational conventions for AAC developed by von Tetzchner and Jensen (1996) (Appendix
After transcription, the co-investigator and a second rater independently reviewed the tapes and transcripts to ensure that interview transcripts accurately recorded the respondents' comments and/or communicative behaviours. The second rater, an undergraduate student, was trained to use transcription protocols (included in Appendix I) by the co-investigator.

**Data Analysis**

Scores and means from the *Communication Survey* and the *QOLP-PD* were calculated using the *Statistical Package for the Social Sciences* (SPSS, Inc., 2000). The participant's personal characteristics (e.g., disability type, age, etc.), life outcomes (e.g., employment status, living circumstances, etc.), communication modes, and communication satisfaction scores are described in written text and within data display tables (Miles and Huberman, 1994).

The *Communication Survey* and *QOLP-PD* of two of the eight participants (25%) were selected at random and re-entered into SPSS to calculate the intra-rater reliability of data entry. Intra-rater reliability was calculated using the following formula: the total number of agreements divided by the number of agreements plus disagreements, multiplied by 100. Intra-rater reliability was found to be 97.6%. All errors were corrected prior to analyzing the data.

**Questions for Individual Analysis**

- **Question #1**: What were the school experiences of the participants with complex communication needs in the study, as measured by the *Communication Survey* and interviews?

- **Question #2**: What are the post-school outcomes for individuals with complex communication needs in the important life domains of education, employment, living
circumstances, and recreational activities as measured by the *Communication Survey* and interviews? What is the quality of life for these individuals as measured by the *QOLP-PD*? Is there an apparent relationship between each person’s *QOLP-PD* scores and their educational, vocational, recreational, and living circumstances outcomes?

- **Question #3:** What modes of communication are currently used by individuals with complex communication needs who participated in the study, and how many continue to use the communication technologies they received in school? Furthermore, how satisfied are these individuals with their ability to communicate for a variety of purposes and in a variety of contexts as measured by the *Communication Survey* and interviews?

**Data Analysis:** To answer all three of these questions, quantitative and qualitative data from the *Communication Survey*, *QOLP-PD* and/or interviews was combined to construct detailed and descriptive “stories” (or narratives) of each participant’s school and post-school life and communication. The stories and data display tables were constructed to permit the emergence of interesting patterns and relationships within and across participant data. A more detailed description of the analysis procedures used for each data set follows.

**QOLP-PD.** Analysis consisted of observing interesting patterns and relationships (a) across the *QOLP-PD* scores of the eight participants and (b) within the *QOLP-PD* data of each participant. More specifically, analysis proceeded by considering each participant’s Total QOL score in relation to: (1) The group’s Total QOL mean score, (2) his or her Total QOL score “ranking” (i.e., in relation to the participants who achieved higher or lower Total QOL scores), (3) the CHP’s categories of “very good,” “adequate,” or “poor” QOL scores, and (4) “notable” scores achieved by the participant in any of the sub-areas. A sub-area score was deemed “notable” if it was two or more points higher or lower than the participant’s
Total QOL score. The “2-point” rule was based on the hypothesis that sub-area scores two points ± the participant's Total QOL score added or detracted value from his/her QOL for personally meaningful and/or important reasons. This hypothesis was borne out in a number of instances in which a “notable” sub-area score intersected with data collected from the Communication Survey or interview—that is, a notably low sub-area score was consistent with reported barriers in a specific life domain. Finally, each participant's Total QOL score and notable sub-area scores were considered in relation to data from the Communication Survey and, where applicable, the participant's interview.

Communication Survey. Data from the Information About You section was organized to provide significant details of the participant's past and current experiences and communication. Analysis of the Your Communication scores consisted of observing interesting patterns and relationships (a) across the of the eight participants' scores and (b) within each participant's scores. More specifically, analysis proceeded by considering each participant's Total Importance and Total Satisfaction scores in relation to: (1) the Total Importance and Total Satisfaction scores achieved by the group (i.e., the participant’s group ranking); (2) the group mean Total Importance and Total Satisfaction scores; (3) the satisfaction categories—i.e., from “not at all satisfied” to “extremely satisfied” indicated by the scores, and (4) “notably” higher or lower scores achieved by the participant in the areas of People, Places, and Functions Communication. “Notably” higher or lower scores were determined following a “0.50-point rule,” based on the hypothesis that scores 0.50 points ± a participant’s Total scores added or detracted value from his/her communication satisfaction for personally meaningful and/or important reasons. Finally, the participant’s Total scores and notable communication area scores were considered in relation to data from the QOLP-
PD (e.g., Total QOL score and notable sub-area scores) and, where applicable, the participant’s interview.

Interviews. Interview transcriptions were analyzed to identify units of text that (1) exemplified the respective participant’s responses to each protocol question (Appendix G); and (2) illustrated, confirmed, or contradicted data from the participant’s the Communication Survey and QOLP-PD. These units—sentences, phrases, key words—were included in the participant narratives.

Questions for Correlational Analysis

Question #4: What is the relationship between the participants’ QOLP-PD scores and their communication Satisfaction scores from the Communication Survey?

Hypothesis: Based on Lund (2001) and Slesaransky-Poe (1997), there will be a positive correlation between participants’ QOLP-PD scores and their Communication Satisfaction scores.

Data Analysis: A Spearman rank-order correlation was calculated to examine the relationships between QOLP-PD scores and communication Satisfaction scores (a Spearman correlation was deemed appropriate given the small sample included in the study). Data displays permitted additional visual analysis of the relationships between the scores.
CHAPTER 3

Results

In this chapter, the results for each of the eight participants are summarized individually in order to answer the research questions. Summary results across participants will also be presented in tables. This will be followed by the results of an analysis of the relationship between the participants' \textit{QOLP-PD} and their Communication Satisfaction scores.

\textit{Questions for Individual Analysis}

- \textit{Question #1}: What were the school experiences of the participants with complex communication needs in the study, as measured by the \textit{Communication Survey} and interviews?

- \textit{Question #2}: What are the post-school outcomes for individuals with complex communication needs in the important life domains of education, employment, living circumstances, and recreational activities as measured by the \textit{Communication Survey} and interviews? What is the quality of life for these individuals as measured by the \textit{QOLP-PD}? Is there an apparent relationship between each person's \textit{QOLP-PD} scores and their educational, vocational, recreational, and living circumstances outcomes?

- \textit{Question #3}: What modes of communication are currently used by individuals with complex communication needs who participated in the study, and how many continue to use the communication technologies (or comparable communication technologies) they received in school? Furthermore, how satisfied are these individuals with their ability to communicate for a variety of purposes and in a variety of contexts as measured by the \textit{Communication Survey} and interviews?
Amy’s Story

Who is Amy?

Amy is 24 years old, has a diagnosis of autism/intellectual disability, and lives in the Lower Mainland. Amy was asked to participate in the study because she received a Wolf communication device from SET-BC approximately three years before leaving high school. Amy currently communicates through manual signs, gestures, photographs, and vocalizations. Her parents, Bill and Deborah, described Amy as a woman of simple pleasures who has a desire to be understood by others and likes to have control over the activities she is involved in. Bill and Deborah completed the Communication Survey and the QOLP-PD on Amy’s behalf. Amy and her parents also participated in an interview in Bill and Deborah’s home. Amy indicated some of her activity and people preferences to the interviewer by pointing to photographs. Otherwise, the interview questions regarding Amy’s school career and current life were answered by her parents.

Amy’s school career

Amy attended elementary school in her local community but spent the majority of her high school years in programs for students with exceptional needs. Bill reported that she loved elementary school, but junior high school was stressful because going from the elementary school where she had really strong supports to the junior high school was tough. He further observed that the junior high school staff was not prepared to support Amy: She was something new to them: they hadn’t seen special kids at the school and they tried but they had no experience....They just couldn’t deal with her. Deborah complained about the school’s lack of involvement and routine and lack of security [provided] for Amy. She noted that the school couldn’t wait to be rid of her.

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1 Quotations follow notation conventions for AAC (von Tetzchner and Jensen, 1996, Appendix H).
At 15, Amy began attending an industrial arts training program for students who had, as Bill put it, social and emotional issues. Deborah described Amy’s experience in the program as just perfect because she was accepted by her peers and because she had a really good teacher: ‘Big Dave’. Amy’s participation in daily educational activities was much greater in the program than it had been in junior high school. Moreover, Amy exhibited much less challenging behaviour than she had in her previous school.

Nonetheless, at 16 Amy began attending and residing at a school program designed especially for students with autism. Bill described Amy’s three years in the program as positive because it gave her more than just academic or school training: They gave her—and taught her—round the clock care in everything: toileting and personal hygiene to cooking...she loved to cook. Deborah was positive about the communication skills they built into her program and noted that she had a great teacher, and that was number one. However, Deborah’s enthusiasm did not extend to Amy’s use of the Wolf communication device that she used during her time in the program (see Amy’s Past and Current Communication below). Moreover, Deborah objected to the fact that the program removed Amy from her local community (it was approximately a 1.5 hour drive from home): I think she lost a lot of her friends, community power, and stability. Amy left the program when she 19. Although she did not receive a high school graduation certificate, Bill and Deborah believed that school adequately prepared Amy for adult life.
Amy's Post-School Life

Amy currently lives with two women in a group home operated by a local adult service agency. At least one support worker is on duty in the home 24 hours per day as Amy requires support for all activities. Amy enjoys swimming, hot-tubbing, hiking, camping, and watching TV and movies—she indicated some of these preferences by pointing to photos during the interview. Amy also enjoys activities involving food such as looking at cookbooks or going to McDonald’s for a hamburger. She happily volunteers at a local fish-hatchery and her parents noted in the Communication Survey that she is “looking for work.”

Amy often attends social events provided by local adult service agencies (e.g., “Funky Fridays”). Bill observed that through these events Amy is slowly re-connecting with some of the friends and acquaintances she lost when she attended the autism program. Amy typically spends one day a week visiting her parents. Deborah commented that when [Amy’s] having fun, she loves being with us: she loves the social contact, she loves the conversation. She shows her happiness by tapping her foot.

Amy’s parents reported a recent improvement in her self-concept. More specifically, Bill noted that her sense that she is in control of things and that she is able to communicate her needs is far better than it used to be. He observed that these improvements have resulted in a reduction in the frequency and intensity of Amy’s challenging behaviour. Bill and Deborah strongly believe that Amy wants to improve her communication skills and ability to control her environment even further (Bill commented that she wants to talk). They view a lack of services—especially one-to-one therapeutic speech services—as the primary barrier to Amy reaching her personal potential. Bill offered the example that if there is one worker for all the women [in Amy’s] home that does nothing for her...it’s custodial care,
maintenance...the only therapy that will work [to teach speech] is one-to-one therapy, and the government doesn't seem interested in doing that.

Amy's QOLP-PD Scores

Table 3.1 displays Amy's scores from the QOLP-PD.
As the table shows, Bill and Deborah assigned Amy a Total QOL score of 0.36, falling just within the “adequate” QOL range (Brown, Raphael, and Renwick, 1997). The score was somewhat lower than the group mean score (2.17); five participants achieved higher Total QOL scores. Amy’s score appears consistent with Bill and Deborah’s sense that Amy’s quality of life is passable but could definitely be improved in a number of areas.
Amy’s only score on the *QOLP-PD* to fall within the “very good” range was achieved in Physical Being (6.58). In other words, in her parent’s view, Amy is satisfied with matters concerning “my body and my health.” On the other hand, Amy achieved three sub-area scores in the “poor” range. Her scores in Community Belonging (“my access to resources”), Leisure Becoming (“things I do for enjoyment”), and Growth Becoming (“things I do to improve myself”) (-5.16, -1.83, and -3.09, respectively) probably reflect Bill and Deborah’s observations that Amy does not have access to the kind of one-to-one services that would enable her to engage in preferred leisure activities or maximize her potential through enhanced speech. Amy’s Decision Making score of 1.9 indicates that her parents believe she perceives herself as having only “a little” control over important areas of her life. Her Opportunities score indicates that her parents believe Amy perceives herself as having only “a few” opportunities in important areas of her life. These scores reflect Amy’s parents’ dissatisfaction with the lack of services available to Amy (especially services that are tailored around Amy’s personal strengths, preferences, and goals).

**Amy’s Past and Current Communication**

As noted previously, Amy currently communicates using approximated manual signs, gestures (e.g., pointing and leading), by gazing at desired items, and by pointing at photographs in her communication book (developed by her group home staff and her parents) and in other available print materials (e.g., flyers and brochures). She communicates for social purposes—e.g., “conversing” about favourite activities or people—by pointing to photographs in photo albums or books (e.g., cook books). Amy vocalizes—sometimes imitating sounds made by others, sometimes whining—to communicate on the phone or to indicate her displeasure with something. Bill described Amy’s challenging behaviour (e.g.,
banging her head on the floor) as an indication of frustration, a response to people not understanding what it is she wants. Bill noted that breakdowns in communication often occur when support workers are unfamiliar with Amy’s subtle communication bids: And usually she’ll look at something and keep glancing at something. But if you don’t know her intimately you don’t know she’s looking at the pop machine or the chocolate bar and that she wants that stuff.

Bill and Deborah were highly critical of the Wolf voice output communication aid that Amy received from SET-BC. Deborah called it a toy and a joke. Their primary criticism of the device was that the display utilized Picture Communication Symbols (line drawings). As Bill put it: The computer used a lot of abstract symbols that [Amy] really couldn’t relate to. As a result, Amy rarely used the device effectively. On the positive side, the device helped Bill and Deborah see that Amy understands and connects with photographic images much more than any other kinds of visual representations. For example, Deborah noted that [Amy] is totally addicted to her flyers—they appeal to her because they have real photos. She can pick everything out of the flyers that come on the weekend. In fact, they have an expression at her group home: ‘Don’t get between me and my flyers!’

Bill and Deborah observed that Amy primarily communicates using gestures and approximated manual signs. Bill reported that Amy uses about 15 manual signs (e.g., signs for DRINK, COOKIE, PLEASE, etc.). Her gestures include shaking her head for ‘no’ or taking someone’s hand and placing it on or near an item she wants. She also says ya for ‘yes’ and, as stated above, Bill and Deborah believe Amy wants to talk as she is continually improving in her vocalizations and is becoming more [vocally] imitative. They recognize that the notion of teaching an adult to speak goes against developmental theory, but believe that
one-to-one therapy focusing on speech should be provided for Amy nonetheless. Deborah said that without more effective avenues of self-expression, Amy’s life will always be limited. Bill stated that Amy will always engage in challenging behaviour as long as other people have to guess the meaning of many of her non-verbal communication attempts.

Amy’s Communication Survey Scores

Table 3.2 displays Amy’s scores from the Communication Survey.

### Table 3.2

**Amy’s Communication Importance and Satisfaction Scores**

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score (1-5)</th>
<th>Satisfaction Score (1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>4.38</td>
<td>1.73</td>
</tr>
<tr>
<td>Places</td>
<td>4.25</td>
<td>2.00</td>
</tr>
<tr>
<td>People</td>
<td>4.37</td>
<td>1.62</td>
</tr>
<tr>
<td>Functions</td>
<td>4.54</td>
<td>1.57</td>
</tr>
</tbody>
</table>

Three participants achieved higher Total Importance scores than Amy and six achieved higher Total Satisfaction scores. Her Total Importance score of 4.38 was higher than the group Total Importance mean score (3.98) while her Total Satisfaction score of 1.73 was lower than the group mean score (2.24). Her scores reflect the fact that Bill and Deborah believed each communication area to be (at least) “very important” to Amy. However, there was slightly more variation across Amy’s satisfaction scores. Her highest Satisfaction score (2.00), achieved in Places Communication, fell in the “not very satisfied” range while her scores in the three remaining areas—Total Communication, People Communication, and
Functions Communication—fell in the “not at all satisfied” range. The difference between Amy’s Importance and Satisfaction scores highlight Bill and Deborah’s perception of a significant gap between her expectations and hopes for her communication and her general dissatisfaction with her actual communication. This dissatisfaction was reflected in Bill’s understanding of how communication breakdowns occur between Amy and the people around her. As he put it: *She knows what she wants, and her needs aren’t complex. So she just doesn’t understand why it takes us so long to figure out what she wants...She has tried and tried and tried to communicate, and you just don’t get it, and she gets frustrated and she will flop down in frustration and be like: ‘you guys are just impossible to deal with!’*

In summary, Amy’s school career was less than adequate but punctuated by a few positive moments. Many of these moments, at least in her parent’s view, could be attributed to the talents and efforts of specific people (e.g., Amy’s teachers). On the other hand, little was done to promote Amy’s communication and the problem persists. In Amy, Bill and Deborah see a person struggling to get her point across and hoping that the right services will enhance her communicative competence and in turn her quality of life. Nonetheless, Amy finds ways to be a part of and contribute to her community (e.g., through recreational, social, and vocational activities).
Cindy’s Story

Who is Cindy?

Cindy is 21 years old, has cerebral palsy, and lives in the Lower Mainland. Cindy was asked to participate in the study because she received a personal computer with Boardmaker and Speaking Dynamically Pro software from SET-BC when she was in high school. Cindy currently communicates using a communication book, gestures, and vocalizations. Cindy’s mother, Joyce, helped her complete the Communication Survey and the QOLP-PD. They reported “my helper and I talked about some of the questions [on the survey] before I gave my final answer.” Cindy and Joyce did not consent to an interview.

Cindy’s school career

Cindy received her education partly in regular classrooms and partly in special education classes. She completed high school at 18 years old but did not receive a graduation certificate. Cindy and her mother reported that she is not sure whether or not high school prepared her for adult life.

Cindy’s Post-School Life

Cindy currently lives with her family and requires support for all activities. She engages in a number of recreational activities including socializing with family and friends, doing sports and outdoor activities (e.g., camping, hiking), playing games (e.g., board games), doing hobbies (e.g., arts and crafts), and going to public places (e.g., coffee shops, the mall). She also does volunteer work, but did not specify what kind or how often.

Cindy’s QOLP-PD Scores

Table 3.3 displays Cindy’s QOLP-PD scores.
Table 3.3

*Cindy’s QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
<td>Physical Being</td>
<td>3.72</td>
</tr>
<tr>
<td></td>
<td>Psychological Being</td>
<td>7.00</td>
</tr>
<tr>
<td></td>
<td>Spiritual Being</td>
<td>5.95</td>
</tr>
<tr>
<td>Total Being</td>
<td></td>
<td>5.55</td>
</tr>
<tr>
<td>Total Belonging</td>
<td>Physical Belonging</td>
<td>9.09</td>
</tr>
<tr>
<td></td>
<td>Social Belonging</td>
<td>8.66</td>
</tr>
<tr>
<td></td>
<td>Community Belonging</td>
<td>5.00</td>
</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td>7.58</td>
</tr>
<tr>
<td>Total Becoming</td>
<td>Practical Becoming</td>
<td>8.00</td>
</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
<td>9.16</td>
</tr>
<tr>
<td></td>
<td>Growth Becoming</td>
<td>9.50</td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td>8.88</td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td>7.47</td>
</tr>
<tr>
<td>Decision Making</td>
<td></td>
<td>3.3</td>
</tr>
<tr>
<td>Opportunities</td>
<td></td>
<td>5.0</td>
</tr>
</tbody>
</table>

As the table shows, Cindy achieved a Total QOL score of 7.47, within the “very good QOL” range. Her score was much higher than the group mean score (2.17) and was the highest Total QOL score in the group. She achieved notably high scores in the sub-domains of Physical Belonging (9.09), Leisure Becoming (9.16), and Growth Becoming (9.50). These scores indicate that Cindy was particularly satisfied with matters concerning “where I live...
and spend my time,” “the things I do for fun and enjoyment,” and “the things I do to improve myself.” Her Growth Becoming score was the highest achieved by any participant and was considerably higher than the next highest score in the group (Kerry at 6.45).

Cindy’s “adequate” Physical Being (“my body and my health”) score (3.72) detracted from her Total QOL more than any other sub-domain and suggested that her health may represent an impediment in her life. Her Community Belonging score of 5.00 also detracted from her Total QOL and indicated that she only marginally satisfied with matters concerning “my access to community resources.”

Cindy’s Decision Making score of 3.3 indicated that she felt she had “some control” over important areas of her life, while her Opportunities score of 5.0, the highest score of all participants in the study, indicated that she believed she had “a great many opportunities” in her life. Taken together, Cindy’s Physical Being, Community Belonging, and Personal Control scores suggest that she felt she had ample opportunities in life but experienced difficulties capitalizing on them due to matters related to her body and health and/or insufficient/inadequate resources. On the other hand, Cindy’s high Growth Becoming score suggests that she is finding ways to develop as an individual regardless of any barriers. It is possible that Cindy’s volunteer work and involvement in a variety of recreational activities play a role in her personal development. Her Practical Becoming Leisure Becoming scores (8.00 and 9.16, respectively) lend support to such a hypothesis (Practical Becoming considers volunteer work).

Cindy’s Past and Current Communication

As mentioned above, Cindy currently communicates using vocalizations, gestures, and a communication book. Cindy received a personal computer with Boardmaker and
Speaking Dynamically Pro software from SET-BC when she was in high school. Cindy and Joyce reported that she was satisfied with the computer and software when she was in school.

Cindy received the communication book that she currently uses from a local rehabilitation hospital (G.F. Strong). Cindy and Joyce appended a written statement to their copy of the Communication Survey indicating that they had were in the process of purchasing a Go Talk 4 communication device from a local assistive technology supplier. They also wrote that Cindy wanted to purchase the computer she used in school “but it was too expensive and SET-BC never gave us many options after school was over. ” The comments suggest that Cindy believes her communication would be enhanced by the use of communication technology comparable to the kind she used in high school. As for support for using such technology, Cindy and Joyce wrote “SET-BC need to have home visits available to [working] families...Families need input into how satisfied or not satisfied they are with the communication set up with their children.” They also reported that they had hoped SET-BC would “contact or follow up” with them after Cindy had left high school, but such a follow-up did not occur.

Cindy’s Communication Survey Scores

Table 3.4 displays Cindy’s scores from the Communication Survey.
### Cindy's Communication Importance and Satisfaction Scores

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score</th>
<th>Satisfaction Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1-5)</td>
<td>(1-5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5.00</td>
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<tr>
<td><strong>People</strong></td>
<td>5.00</td>
<td>3.33</td>
</tr>
<tr>
<td><strong>Places</strong></td>
<td>5.00</td>
<td>2.62</td>
</tr>
<tr>
<td><strong>Functions</strong></td>
<td>5.00</td>
<td>2.80</td>
</tr>
</tbody>
</table>

Cindy achieved the highest Total Importance score in the group (5.00; tied with Kerry and Dianne) and the second highest Total Satisfaction score. Her Total Importance score was higher than the group mean score (3.98) but only somewhat higher than the group mean Total Satisfaction score (2.24). Her satisfaction scores ranged from a low of 2.62 in Places communication to a high of 3.33 for People communication. On the one hand, these scores, together with her Total communication satisfaction score of 2.92, indicate that Cindy is generally satisfied with her communication—these observations provide evidence that Cindy’s communication contributes positively to her “very good” QOL. On the other hand, the difference between Cindy’s Total Importance and Total Satisfaction score indicates that her communication is not meeting her expectations and that she believes it could be improved. The latter proposition is consistent with Cindy’s upcoming purchase of a high-tech communication device and her desire for further and on-going professional AAC support (i.e., from SET-BC or a comparable adult service agency). Indeed, Cindy’s relatively low
Community Belonging score on the *QOLP-PD* is consistent with the apparent lack of AAC support and services available to her and her family.

*Dianne’s Story*

*Who is Dianne?*

Dianne is 22 years old, has Rett Syndrome, and lives in the Lower Mainland. Dianne currently communicates using a blink-and-eye-gaze system, gestures, and vocalizations. She was asked to participate in the study because she received a Ke:nx switch and a Big Mack from SET-BC when she was in high school. Dianne’s mother, Janet, described her daughter as a loving, communicative, independent but often frustrated individual. Janet completed the *Communication Survey* and the *QOLP-PD* on Dianne’s behalf. An interview was conducted in Janet’s home with Dianne and Janet. Dianne answered a number of the interview questions by blinking for ‘yes’ and not responding for ‘no’ and by gazing at ‘yes/no’ cards. Janet answered questions that she felt Dianne was not able to answer.

*Dianne’s School Career*

Dianne received her education in her local community, mostly in resource rooms and special education classes. She completed high school at 19 but did not receive a graduation certificate. During the interview, Dianne began to cry when asked if she enjoyed high school. Janet explained that Dianne *loved every aspect* of school and continues to miss it. *It gave a very good structure to her day and she saw her friends. Melanie and Paul [her friends] read to her...The whole ambiance of school and going and seeing everybody and all the activity and the noise and people...She loved going to music, she loved going to gym class. She loved drama: that was her favourite. She had wonderful classroom aides, one after the other. The teachers were wonderful.*
Despite Dianne’s love for school, Janet felt that high school did not prepare her
daughter for adult life. She complained about a school practice whereby the classroom aides
didn’t work with any person for more than two years. Consequently, in Janet’s view, the
aides lacked sufficient training to properly teach and support Dianne (despite being skilled
and well-intentioned individuals). Janet’s primary complaints about Dianne’s school career,
however, concerned the services she received from SET-BC (see Dianne’s Past and Current
Communication below).

*Dianne’s Post-School Life*

Janet explained that Dianne sleeps here [her mother and father’s home] Monday and
Thursday and she has her own home as well... She lives on her own and she has caregivers
who come in. They come in from 9 to 3 [o’clock], 3 to 9 [o’clock], and overnight. Dianne
blinked ‘yes’ when asked if she liked her home.

Dianne requires support for all activities. She receives this support from her family
and a team of support workers (3 to 5 individuals) who are trained by Janet. Janet explained
that Dianne’s family and team help her lead as normal a life as possible and described her as
being busier than most people. Dianne’s daily routine includes swimming, jogging, or
working out with an active therapy machine. Beyond this routine, she goes disabled skiing,
boating, sailing. She goes to see her 2 year-old niece who she is crazy for. And she has
friends who come. She has a little girl friend who is disabled who comes to dinner and goes
out with her—yesterday they went swimming together. Dianne goes swimming on Saturdays
with her friends and then to the mall for lunch. She does her own shopping. She can walk
through the Safeway and push the cart. Janet also reported that Dianne volunteers at a
preschool every Monday, has a boyfriend whom she sees roughly once per week, and enjoys
having books read to her. Dianne blinked ‘yes’ when asked if she would like to have a job. Janet concluded that Dianne is certainly someone who is happy to get up in the morning and looks forward to her day.

On a less positive note, Janet pointed out that Dianne has a good deal of time on her hands because, unlike most typical adults, she does not work. She described the challenges associated with helping Dianne stay active and engaged. For instance, Dianne’s limited use of her hands (a characteristic of Rett Syndrome) and consequent need for support limit her opportunities to try new activities and enhance her lifestyle. Janet explained that if you don’t have the fine motor coordination for painting and handicrafts and puzzles it’s pretty challenging to always find something new to do... And there comes a point where she doesn’t want to go swimming or to the track because she goes most days... If she could sail in May, June, July, August, and September rather than just July and August [the months when supported sailing occurs] obviously that would be nice, but it’s not possible. From Janet’s perspective, the limitations on Dianne’s lifestyle make it particularly difficult for her to contend with the typical irritants of adult life. Janet observed that while Dianne’s sadness about missing friends or not being able to communicate with distant relatives are the kinds of issues we all have, we all have so much more richness in our lives that these things doesn’t matter as much to us [as they do to her].

Janet attributed the positive aspects of Dianne’s life to factors within Dianne and to the people who have supported her, both directly and indirectly. [Dianne] is certainly somebody who has a really nice disposition and part of that I always thought was due to her but it is also certainly because of her care. Janet observed that Dianne has had a parade of outstanding people. Her principals at school... she has had marvelous people. I would have a
tough time coming up with fifteen people in the last 24 years that I’ve had a problem with.

For her own part, Janet noted that I really tune Dianne’s program from week to week. She has been my life for the past 24 years.

_Dianne’s QOLP-PD Scores_

Table 3.5 displays Dianne’s scores from the _QOLP-PD_.

Table 3.5

*Dianne’s QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
<td></td>
<td>4.58</td>
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<tr>
<td></td>
<td>Physical Being</td>
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<tr>
<td></td>
<td>Psychological Being</td>
<td><strong>5.00</strong></td>
</tr>
<tr>
<td></td>
<td>Spiritual Being</td>
<td><strong>5.00</strong></td>
</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td>4.16</td>
</tr>
<tr>
<td></td>
<td>Physical Belonging</td>
<td><strong>5.00</strong></td>
</tr>
<tr>
<td></td>
<td>Social Belonging</td>
<td>7.50</td>
</tr>
<tr>
<td></td>
<td>Community Belonging</td>
<td>0.00</td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td>-1.66</td>
</tr>
<tr>
<td></td>
<td>Practical Becoming</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>Growth Becoming</td>
<td><strong>-5.00</strong></td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td><strong>2.36</strong></td>
</tr>
</tbody>
</table>

| Decision Making (+1 to +5) | 1.7 |
| Opportunities (+1 to +5)   | 3.0 |

As the table shows, Janet assigned Dianne a Total QOL score of 2.36, in the “adequate” range. Her score was very close to the group mean score (2.17); two participants achieved higher Total QOL scores. Dianne’s Psychological Being (“my thoughts and feelings”) score of 5.00 was notably higher than her Total QOL score and was, on the one hand, consistent with Janet’s description of her *nice disposition* but, on the other hand,
somewhat inconsistent with Janet’s analysis of her difficulties coping with typical adult frustrations. Her Spiritual Being (“my beliefs and values”) score of 5.00 was also notable and reflects comments made by Janet to the effect that Dianne knows what she wants (e.g., I think the only thing she would tell you is she would like to communicate better [and] that she would like to use her hands). Dianne’s Social Belonging score of 7.50 added considerable value to her Total QOL score and was consistent with Janet’s description of her affectionate nature and extensive social life (e.g., interacting with friends and family members, having a boyfriend, etc.). Her Physical Belonging score (“where I live and spend my time”) of 5.00, falling just within the “very good” range, is in accord with Dianne’s comment regarding her satisfaction with her living situation.

Dianne’s Community Belonging (“my access to community resources”) score of 0.00—almost within the “poor” range—is not surprising in light of Janet’s dissatisfaction with the dearth of AAC services and supports available to her daughter (see Diane’s Past and Current Communication below). In addition, Dianne’s “poor” Growth Becoming (“the things I do to grow and change”) score of -5.00 is congruent with Janet’s statements regarding the challenges involved in expanding Dianne’s lifestyle (e.g., her fine motor limitations, her need for pervasive support). Her Decision Making score of 1.7—indicating that Dianne had, at best, “a little” control over important areas of her life—possibly stems from Janet’s depiction of Dianne as being trapped within herself, aware of her desires but limited in her capacity to influence her world (see below).

Dianne’s Past and Current Communication

As mentioned above, Dianne currently communicates by blinking for ‘yes’ and not responding for ‘no,’ and by gazing at written words, symbols, photographs, and objects. She
participated in the interview to a considerably greater extent than any of the other interviewed participants (answering ‘yes/no’ questions about school, her family, her current home, etc.). Janet is very aware, and trains Dianne’s support workers to be very aware, of the meanings of Dianne’s gestures (e.g., biting her hand, breathing patterns), vocalizations (e.g., moans) and facial expressions (e.g., furrowed brows). Dianne started using visual-graphic forms of communication as a young child. Janet described how a private Speech-Language Pathologist, whom she called a lifesaver, got us started with five or six pictures depicting some of Dianne’s basic wants and needs. Janet and her family gradually built Dianne’s communication system and were soon sold on the need for further AAC intervention. In fact, Janet explained, the reason [Dianne’s] school district got someone who was supposed to start working in augmented communication was because...I kicked up such a fuss that they finally brought people in to do augmentative communication. Janet listed the various low technology and unaided communication modes Dianne was assisted to use throughout her school career: sign language, ‘yes/no’ signs, she had Bliss symbols, she had a trifold. Janet explained that Dianne rarely uses Bliss symbols now because we’ve never had a staff that was very compliant with Bliss symbols.

In high school, Dianne received a Ke:nx switch (an keyboard and mouse emulator) and a Big Mack (a single-switch voice output aid) from SET-BC. Dianne reported that she enjoyed being assisted to use her Ke:nx switch to, as Janet put it, write stories on the computer. Janet further explained that, to her knowledge, Dianne used the Big Mack in face-to-face communication situations at school a little bit...but not as much as they should have. In Janet’s opinion, Dianne was not supported to adequately use either piece of technology because of the unique challenges posed by Rett Syndrome. SET-BC got involved with her
when they first started to do the CP students, and that's who they were really interested in...She has very limited hand use, and so that was a bit of a stretch for them and they weren't interested in stretching. Not surprisingly, Janet felt that Dianne was not very satisfied with the technology she received from SET-BC in high school.

Despite her misgivings about Dianne’s SET-BC services, Janet asked the school to send Dianne’s technology home during non-school times because students are only at school 5 hours a day. Janet requested that she be trained to use the technology so that she could transfer everything Dianne was learning at school to home. However, SET-BC, Janet claimed, don’t want to work with people at home, and there is no funding [to do so]. She also wanted Dianne to keep her Ke:nx switch after leaving school because you don’t teach somebody something and then take it away. Unfortunately, SET-BC informed her that such an arrangement was not possible because the switch belonged to them. I would have bought it, she continued, and I would go back today and buy it if they are going to sell me one...If someone would just tell me where to get it and if I could pay someone from SET-BC for 3 hours to come here and show me how to use if I would be happy to pay for it.

When Dianne was asked about things she would like to change in her life, Janet replied that, I think the only thing she could tell you is she would like to communicate better [and] that she would like to use her hands. Specifically, Janet reported that Dianne would like to be able to communicate with distant friends and family more effectively (i.e., using the telephone); Dianne reported that she would like to be able to write with a pen (i.e., so she could write letters). Janet lamented the lack of resources available to improve Dianne’s overall communication. She argued that Dianne’s quality of life would be several thousand percent better if she had access to communication equipment and an augmentative
communication person who would be responsive to Dianne's unique needs. I can go to a store and look at all of the communication equipment but they are so expensive and because most of them involve finger pointing. What she needs is an eye gaze thing with the light. She summarized Dianne's predicament by comparing her to an individual who has suffered a stroke and is unable to talk but left without services: If somebody has had a stroke it doesn't mean they have lost their brainpower... She is intelligent, she is physically disabled... [and] it's a sad part of Dianne's life and everybody else's that she's in there thinking and she is really trapped like a stroke victim. She concluded that, it's crazy that Dianne was eligible for government funding for AAC when she was a student (i.e., through SET-BC) but has not received comparable funding or services since turning 19.

Dianne's Communication Survey Scores

Table 3.6 displays Dianne's scores from the Communication Survey.

Table 3.6

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score</th>
<th>Satisfaction Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1-5)</td>
<td>(1-5)</td>
</tr>
<tr>
<td>Total</td>
<td>5.00</td>
<td>2.00</td>
</tr>
<tr>
<td>People</td>
<td>5.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Places</td>
<td>5.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Functions</td>
<td>5.00</td>
<td>2.00</td>
</tr>
</tbody>
</table>

As the table shows, Dianne achieved the highest Total Importance score (5.00; tied with Cindy and Kerry); however, five participants achieved higher Total Satisfaction scores.
Her Total Importance score was higher than the group mean (3.98) while her Total Satisfaction score was just below the group mean (2.24). These scores indicate that Janet felt that each communication area was “extremely important” to Dianne and that she was “somewhat satisfied” with her communication in each area. This difference between Dianne’s Importance scores and Satisfaction scores are, again, consistent with Janet’s depiction of Dianne being trapped within a body that prohibits her from connecting with the world in the way in the way she wants. Indeed, the foregoing picture of Dianne presents a woman who has a zest for life who, on the one hand, enjoys a number of fulfilling social and recreational activities but, on the other hand, is frustrated by her physical and communicative challenges. The “adequate” Total QOL score of 2.36 assigned to her by Janet seems appropriate given this picture.

Jason’s Story

Who is Jason?

Jason is 19 years old, has a diagnosis of autism and intellectual disability, and lives with his family in the Lower Mainland. Jason currently communicates through gestures, vocalizations, and some speech (approximately 10 two- to three-word phrases). Jason is a cautious, silent young man. He was asked to participate in the study because he received a PC desktop computer with Boardmaker software from SET-BC when he was in high school. Jason’s mother, Lisa, completed the Communication Survey and the QOLP-PD on Jason’s behalf. An interview was conducted in Jason’s family home with Jason and Lisa. During the interview, Jason showed signs of nervousness and confusion when asked questions (e.g., rocking his body back and forth, worried facial expressions). Lisa reported that Jason was not
able to understand nor answer the interview questions; accordingly, she answered on his behalf. The family speaks both Cantonese and English at home.

Jason's School Career

Jason received his education in his home community, partly in regular classrooms and partly in special education classes. He completed high school just after turning 19 but did not receive a graduation certificate. Lisa reported that, in her opinion, high school did not prepare Jason for adult life. Lisa stated that Jason was very happy in school. *I know he liked school because of his reaction when he sat in school. He clapped his hands and he looked quite happy.* More specifically, Jason liked school because *he liked the people, he liked his teacher. He liked the atmosphere and environment there.*

Jason's Post-School Life

Jason lives with his mother, father, and brother. He requires assistance for all activities. Jason recently started attending a day program operated by a local adult service agency. Lisa reported that the program was only the service that Jason had received or been offered since leaving high school 6 months ago. She stated that the family had considered moving out of their current community but decided to stay so that Jason could attend the day program. Lisa felt positive that Jason would enjoy the program because it would enable him to engage in his preferred activities: playing basketball and going bowling. On the other hand, she was concerned that Jason would not acquire any new skills in the program. *From what I can see, mostly the girls [Jason's support workers] just baby sit and take him out to the mall and outgoing activities. I don't think they can teach him anything.* Lisa pointed out that the staff at the program had told her that they were beginning to teach Jason to use
manual signs. Although Lisa was hopeful that someone would teach Jason new
communication skills, she felt that the program workers were not qualified to do so.

Lisa’s description of Jason’s current life revolved around changes that had occurred
in his behaviour since his grandmother’s death three years earlier. Before his grandma was
staying at home all the time to look after him. Then his grandma passed away...At this time,
Jason changed. Lisa observed that prior to losing his grandmother, Jason was very
disciplined. He followed his routine from morning to night; you didn’t have to tell him what
to do. She reported that Jason currently lacks motivation to participate in family routines and
activities and often exhibits challenging behaviour: he doesn’t do anything, he gave up. He
needs to be prompted to do anything, he always needs attention and wants you with him...he
has lots of behaviour problems. She added that Jason had experienced an increase in epileptic
seizures over the past few years and conjectured that recent increases in the daily dosage of
his seizure medication might have triggered the changes in her son’s behaviour: I’m not sure
if it’s the medicine, but he won’t let people take blood for a blood test. He is so strong and he
won’t let people do it.

When asked about possible ways to help Jason, Lisa complained that, I’m looking for
help, but no one can help me. I asked the social worker, but no one ever calls me back. I
asked the doctor and he has no comment. This is why I think I have to see the
psychiatrist....But it’s a long waiting list for him. Lisa commented that she was frustrated by
the fact that Jason doesn’t use his skills and I don’t know what he is thinking...no one knows.

Jason’s QOLP-PD Scores

Table 3.7 displays Jason’s scores from the QOLP-PD.
Table 3.7

*Jason's QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
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</tr>
<tr>
<td></td>
<td>Physical Being</td>
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<td>Psychological Being</td>
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<td></td>
<td>Spiritual Being</td>
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<tr>
<td>Total Belonging</td>
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<td>Physical Belonging</td>
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<td></td>
<td>Social Belonging</td>
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<td></td>
<td>Community Belonging</td>
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<tr>
<td>Total Becoming</td>
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<td></td>
<td>Practical Becoming</td>
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</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
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<td></td>
<td>Growth Becoming</td>
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<td>Total QOL</td>
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<tr>
<td>Decision Making (+1 to +5)</td>
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<td>2.5</td>
</tr>
<tr>
<td>Opportunities (+1 to +5)</td>
<td></td>
<td>1.5</td>
</tr>
</tbody>
</table>

As the table shows, Lisa assigned Jason a Total QOL score of -3.30, within the "poor" QOL range. His score was considerably lower than the group mean score (2.17) and was the lowest Total QOL score in the group. Jason’s score reflects Lisa’s description of her son as having a limited activity pattern and lacking both the motivation and resources to make changes in his life.
Jason’s Physical Belonging score of 4.20 was considerably higher than his Total QOL score. The score indicates that, in Lisa’s opinion, matters concerning “where I live and spend my time” are more or less satisfactory for Jason. His Social Belonging score of 0.00 was also higher than his Total QOL score but nonetheless indicated that, in Lisa’s opinion, matters concerning Jason’s relationships and fit with “the people around me” were only marginally satisfactory for her son.

Jason achieved a score of −7.50 on both Psychological Being (“my thoughts and feelings”) and Spiritual Being (“my beliefs and values”). These scores reflect Lisa’s frustration regarding Jason’s apparent lack of motivation to care about his life and/or change his outlook on life. His Becoming Growth score of −6.28 is consistent with this pattern and can be linked to Lisa’s report that Jason appears disinterested in trying anything new: *with autism, it is very difficult to change their routines.* Finally, Lisa answered “Don’t Know” to each Practical Becoming item, presumably because Jason does not show signs of being concerned with practical activities of daily living.

Finally, Jason’s Opportunities and Decision Making scores (1.5 and 2.5, respectively) indicated that Jason had “some” opportunities and “a little” control over important areas of his life. These scores are somewhat incongruent with Lisa’s statements in the interview regarding Jason’s lack of access to resources and services and his limited abilities to express his thoughts and feelings (see the next section).

*Jason’s Past and Current Communication*

As noted previously, Jason currently communicates through gestures, vocalizations, and some speech (approximately 10 two- to three-word phrases). Lisa felt that Jason was not very satisfied with the PC desktop computer with Boardmaker software that he received from
SET-BC in high school. She commented: *It didn't help him to talk, just helped him to spend his time.* Lisa noted that Jason also used pictures and/or photographs to communicate in high school. Jason did not take the computer with him when he left school. Lisa said that she would like him to have a comparable computer at home because he has nothing to do. She also lamented about the limitations of Jason’s current communication abilities, noting: *he cannot express his feelings, you just have to look at his face and try to tell.* When describing Jason’s speech, she observed that he rarely initiates communication: *He doesn’t say [the words he knows], it’s only when you ask. I will ask him if he wants juice and he will say: ‘I want juice’.* Although Lisa did not describe the topography of Jason’s challenging behaviour, it was clear that it commonly assumed the form of physical but passive resistance (e.g., not allowing health workers to take blood samples).

*Jason’s Communication Survey Scores*

Table 3.8 displays Jason’s scores from the *Communication Survey*.

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score (1-5)</th>
<th>Satisfaction Score (1-5)</th>
</tr>
</thead>
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<tr>
<td>Total</td>
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<td>1.00</td>
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<tr>
<td>People</td>
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<tr>
<td>Places</td>
<td>4.00</td>
<td>1.00</td>
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<tr>
<td>Functions</td>
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<td>1.00</td>
</tr>
</tbody>
</table>
Four participants achieved higher Total Importance scores than Jason; however, he achieved the lowest Total Satisfaction score (1.00). His Total Importance score of 4.00 was just above the group mean (3.98) while his Total Satisfaction score was considerably lower than the group mean (2.24). These scores indicate that Lisa believed each communication to be “very important” to Jason and that he was “not at all satisfied” with his communication in each area. The difference between Jason’s Importance scores and Satisfaction scores are consistent with Lisa’s disappointment with Jason’s communication and lack of motivation to communicate. On the other hand, the Importance scores accorded to Jason by Lisa are incongruous with her reports of his motivational difficulties. Either way, the foregoing picture of Jason presents a man who is disengaged from and (and at least somewhat) frustrated with his world—his Communication Survey and QOLP-PD scores certainly fit this picture.

Jeremy's Story

Who is Jeremy?

Jeremy is 22 years old, has cerebral palsy, and lives in the Lower Mainland. Jeremy was asked to participate in the study because he received an Intro Talker from SET-BC when he was in high school. Jeremy’s mother, Susan, reported that he currently communicates by pointing and through vocalizations. In a brief telephone conversation, she described Jeremy as an effective communicator. Susan completed the Communication Survey and the QOLP-PD on his behalf but did not consent to an interview.

Jeremy’s school career

On the Communication Survey, Susan reported that Jeremy received his education mostly in resource rooms and special education classes. Jeremy completed his high school at
19 but did not receive a graduation certificate. Susan believes that school did not prepare Jeremy for adult life.

Jeremy's Post-School Life

Jeremy currently lives with his family and requires support for all activities. In the telephone conversation, Susan described Jeremy as being *trapped in his body*, making it difficult for him to be independent to the extent he would like to be. She reported that he has been waiting to attend some kind of community-based day program; however, he has been deemed too intellectually capable for some programs and too physically dependent for others. Susan concluded that *it's a black hole out there* for adults with disabilities seeking services and supports. She listed Jeremy's recreation and leisure activities as socializing with family and friends, watching TV and movies, and going to public places (e.g., coffee shops, the mall).

Jeremy's QOLP-PD Scores

Table 3.9 displays Jeremy’s *QOLP-PD* scores.
### Table 3.9

*Jeremy's QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
<td></td>
<td>2.59</td>
</tr>
<tr>
<td></td>
<td>Physical Being</td>
<td>2.40</td>
</tr>
<tr>
<td></td>
<td>Psychological Being</td>
<td>2.44</td>
</tr>
<tr>
<td></td>
<td>Spiritual Being</td>
<td>2.94</td>
</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td>3.01</td>
</tr>
<tr>
<td></td>
<td>Physical Belonging</td>
<td>6.33</td>
</tr>
<tr>
<td></td>
<td>Social Belonging</td>
<td>4.45</td>
</tr>
<tr>
<td></td>
<td>Community Belonging</td>
<td>-1.75</td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td>1.33</td>
</tr>
<tr>
<td></td>
<td>Practical Becoming</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
<td>3.08</td>
</tr>
<tr>
<td></td>
<td>Growth Becoming</td>
<td>0.93</td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td><strong>2.31</strong></td>
</tr>
</tbody>
</table>

| Decision Making (+1 to +5) | 2.0 |
| Opportunities (+1 to +5)   | 3.0 |

As the table shows, Susan assigned Jeremy a Total QOL score of 2.31, in the middle of the “adequate” QOL range. His score was slightly higher than the group mean score (2.17); three participants achieved higher Total QOL scores. Jeremy’s highest sub-domain score was in Physical Belonging (6.33). This score means that Susan feels that matters concerning “where I live and spend my time” are “very good” for Jeremy. His Social
Belonging score (4.45) was notably higher than his Total QOL suggesting that, in Susan’s opinion, matters concerning “the people around me” add value to her son’s quality of life.

On the other hand, Jeremy’s Community Belonging score (-1.75) and his Practical Becoming score (0.00) indicate that Susan believes matters concerning “my access to community resources” and “the daily things I do” are less than satisfactory for her son. Based on Susan’s comments in the telephone conversation, it is likely that these scores reflect the fact that Jeremy currently does not participate—or does not receive sufficient services and supports to participate—in vocational and/or educational activities.

Jeremy’s Decision Making and Opportunities scores of 2.0 and 3.0 respectively indicate that Susan feels her son has only “a little” control over important areas of his life and only “a few opportunities” in life. Again, these scores are apparently associated with Jeremy’s insufficient access to satisfactory support, services, and/or funding and resultant feelings that he has little capacity or opportunities to shape his life.

Jeremy’s Past and Current Communication

As mentioned above, Susan reported that Jeremy currently communicates by pointing and through vocalizations. In the telephone conversation, Susan observed that despite his physical limitations, Jeremy effectively communicates for his wants and needs: he’ll let you know what he wants that little finger! She stressed Jeremy’s strong receptive language skills, remarking that he understands everything you say to him. Jeremy received an Intro Talker (a voice output communication aid) from SET-BC. Susan reported that Jeremy was “very satisfied” with the communication device when he was in high school and wished that he had a comparable device at present. Unfortunately, the Intro Talker is now too old to be used in an efficient or effective way.
Jeremy's Communication Survey Scores

Table 3.10 displays Jeremy's scores from the Communication Survey.

Table 3.10
Jeremy's Communication Importance and Satisfaction Scores

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score (1-5)</th>
<th>Satisfaction Score (1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>2.26</td>
<td>2.36</td>
</tr>
<tr>
<td>People</td>
<td>1.87</td>
<td>2.00</td>
</tr>
<tr>
<td>Places</td>
<td>2.00</td>
<td>2.50</td>
</tr>
<tr>
<td>Functions</td>
<td>2.93</td>
<td>2.57</td>
</tr>
</tbody>
</table>

Based on Susan's ratings, Jeremy achieved the lowest Total Importance score in the group (2.26) and the third highest Total Satisfaction score. His Total Importance score was considerably lower than the group mean (3.98) while his Total Satisfaction score of 2.36 was just above the Total Satisfaction group mean (2.24). Susan's ratings indicated that she believed that Jeremy was generally "not very satisfied" with his communication. Jeremy's relatively low Importance scores and the general congruence between his Importance and Satisfaction scores indicate that, from Susan's perspective, Jeremy is somewhat dissatisfied with his communication but is not terribly motivated to improve it.

Nonetheless, it does not seem surprising that an individual who was very satisfied with his use of a communication technology such as an Intro Talker in high school is not very satisfied with his current communication if the latter was limited to gestures and vocalizations. The discrepancy between Susan's reports of Jeremy's level of satisfaction with the community technology he used in high school and his current lack of access to a
comparable technology partly accounts for his “poor” Community Belonging (“my access to resources”) score on the QOLP-PD (i.e., -1.75).

The foregoing picture of Jeremy’s presents a man who is somewhat satisfied with his life but lacks needed skills (including communication skills) and opportunities to improve his situation. Jeremy’s QOLP-PD scores suggest that while his basic physical and social needs have been met, he is not satisfied with his connections with and opportunities to participate in society.

Kerry’s Story

Who is Kerry?

Kerry is 24 years old, has cerebral palsy, and lives in the Okanagan. Kerry was asked to participate in the study because she received an Apple laptop computer with word-processing software from SET-BC when she was in high school. Kerry currently communicates in face-to-face contexts using an eye gaze system and uses her Apple computer for writing. Kerry completed the Communication Survey and the QOLP-PD with help from her mother, Carol. They reported that “my helper and I talked about all of the questions [on the surveys] before I gave my final answer.” Kerry did not consent to an interview.

Kerry’s school career

Kerry received her education partly in regular classrooms and partly in special education classes. She completed high school at 20 but did not receive a graduation certificate. Kerry feels that high school did not prepare her for adult life.
Kerry's Post-School Life

Kerry currently lives with her family and requires support for all activities. She reported engaging in a number of recreation activities including socializing with family and friends, doing outdoor activities (e.g., camping, hiking), playing games (e.g., board games), reading, watching TV and movies, and going to public places (e.g., coffee shops, the mall).

Kerry's QOLP-PD Scores

Table 3.11 displays Kerry’s QOLP-PD scores
Table 3.11

*Kerry’s QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical Being</td>
<td>6.85</td>
</tr>
<tr>
<td></td>
<td>Psychological Being</td>
<td>9.40</td>
</tr>
<tr>
<td></td>
<td>Spiritual Being</td>
<td>8.77</td>
</tr>
<tr>
<td></td>
<td><strong>Score</strong>: 8.25</td>
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</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical Belonging</td>
<td>9.09</td>
</tr>
<tr>
<td></td>
<td>Social Belonging</td>
<td>8.66</td>
</tr>
<tr>
<td></td>
<td>Community Belonging</td>
<td>1.72</td>
</tr>
<tr>
<td></td>
<td><strong>Score</strong>: 6.45</td>
<td></td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Practical Becoming</td>
<td>3.00</td>
</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
<td>9.58</td>
</tr>
<tr>
<td></td>
<td>Growth Becoming</td>
<td>6.54</td>
</tr>
<tr>
<td></td>
<td><strong>Score</strong>: 6.37</td>
<td></td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td><strong>Score</strong>: 7.05</td>
</tr>
</tbody>
</table>

| Decision Making (+1 to +5) | 4.6          |
| Opportunities (+1 to +5)   | 3.7          |

As the table shows, Kerry achieved a Total QOL score of 7.05, within the “very good QOL” range. Kerry’s score was much higher than the group mean score (2.17) and was the second highest score in the group. She achieved notably high scores in the sub-domains of Psychological Being (9.40), Physical Belonging (9.09), and Leisure Becoming (9.58). These scores indicate that Kerry was particularly satisfied with matters concerning “my thoughts...
and my feelings,” “where I live and spend my time,” and “the things I do for fun and enjoyment.” The latter score is understandable given the extensive list of recreational activities Kerry reported enjoying.

On the other hand, Kerry’s “adequate” Community Belonging and Practical Becoming scores (1.72 and 3.00, respectively) indicated that she was somewhat displeased with matters concerning “my access to community resources” and “the daily things I do.” Perhaps Kerry felt that she had insufficient access to services and supports to be able to engage in meaningful and/or productive activities (e.g., educational and/or additional vocational activities).

Kerry’s Decision Making scores of 4.6 (the highest score in the group) indicated that she felt she had a “quite a bit of control” over important areas of her life, while her Opportunities score of 3.7 (also the highest score of all participants in the study) indicates that she believed she had “many opportunities” in her life. Considering her Personal Control scores together with her Practical Becoming and Community Belonging scores again suggests that Kerry felt that she had opportunities to expand her horizons but lacked the means (e.g., external resources) to do so.

**Kerry’s Past and Current Communication**

As mentioned above, Kerry currently communicates in face-to-face situations using an eye gaze system in which she gazes at a communication book developed by her family. Carol explained in a telephone conversation that the communication book contains a combination of written words, letters, and/or symbols. Carol commented that Kerry has used her eye gaze system for a number of years and is now very fluent with it. With familiar people, Kerry can communicate quickly and effectively using the system and gets most of
her needs met this way. In fact, Carol reported that with familiar people, Kerry is able to reproduce the eye movements needed to locate specific messages in her communication book without the book being present. Again, Kerry used an Apple laptop computer for writing when she was in high school (she used a head switch to operate the computer). She reported that she was "very satisfied" with the computer in high school and is currently "satisfied" with it. Carol noted that Kerry no longer uses her computer very often.

**Kerry's Communication Survey Scores**

Table 3.12 displays Kerry's scores from the *Communication Survey*.

Table 3.12

*Kerry's Communication Importance and Satisfaction Scores*

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score (1-5)</th>
<th>Satisfaction Score (1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
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<td>3.71</td>
</tr>
<tr>
<td>People</td>
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<td>3.00</td>
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<tr>
<td>Places</td>
<td>5.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Functions</td>
<td>5.00</td>
<td>4.64</td>
</tr>
</tbody>
</table>

Kerry achieved the highest Total Importance score (5.00; tied with Cindy and Dianne) as well as the highest Total Satisfaction score (3.71); both scores were notably higher than the group mean scores (3.98 and 2.24, respectively). Kerry's relatively high Total Satisfaction score is consistent with Carol's comments regarding Kerry's competence with her eye gaze system. Having said that, it is interesting that her Satisfaction scores ranged from a low of 3.00 in Places and People Communication to a high of 4.64 for Functions Communication. These scores indicate that while Kerry was almost "extremely satisfied"
with her capacity to communicate in activities of daily living, she was only “satisfied” with
to communicate with various people in various places. Perhaps the discrepancy between
these scores can be accounted for on the basis Kerry’s fluency with familiar partners, i.e.,
that her functional communication predominantly occurs with familiar people and is
therefore highly satisfying while her communication in the other areas is more likely to occur
with less or non-familiar people and is therefore less satisfying. Indeed, it is possible that
Kerry’s reliance on familiar communication partner posits a barrier to her participation in
vocational or educational environments. Perhaps one of the resources she lacks is the means
to train new communication partners in new settings.

In summary, the factors that contribute most to Kerry’s high QOL include her frame
of mind, her living circumstances, her relationships and her recreational pursuits. On the
other hand, she is much less satisfied with her access to resources and with her daily,
practical activities (possibly a reflection of the fact that she is not involved in vocational or
educational activities). Kerry is also generally satisfied with her communication. A
contributing factor in that regard appears to be the fact that she has been using her eye gaze
system for a number of years.

Naomi’s Story

Who is Naomi?

Naomi is 23 years old, has an intellectual disability, and lives on Vancouver Island.
Naomi was asked to participate in the study because she received an Alpha Talker from SET-
BC when she was in high school. Naomi currently communicates using speech (fewer than
10 words), vocalizations, gestures, and a communication book with picture symbols.
Naomi’s mother, Leanne, completed the Communication Survey and the QOLP-PD on her daughter’s behalf. Naomi’s family did not consent to an interview.

*Naomi’s School Career*

Leanne reported that Naomi received her education mostly in resource rooms and special classes. Naomi completed her high school program at 19 but did not receive a graduation certificate. Leanne believes that high school did not prepare Naomi for adult life.

*Naomi’s Post-School Life*

Naomi currently lives in a group home and requires support for all activities. She works in a sheltered workshop. Leanne reported that Naomi enjoys socializing with friends and family, playing games (e.g., board games), watching TV and movies, and visiting public places (e.g., coffee shops).

*Naomi’s QOLP-PD Scores*

Table 3.13 displays Naomi’s QOLP-PD scores.
Table 3.13

*Naomi’s QOL-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
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<td>0.68</td>
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<tr>
<td></td>
<td>Physical Being</td>
<td>0.36</td>
</tr>
<tr>
<td></td>
<td>Psychological</td>
<td>0.72</td>
</tr>
<tr>
<td></td>
<td>Spiritual</td>
<td>0.97</td>
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<td>Being Score</td>
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<tr>
<td>Total Belonging</td>
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<tr>
<td></td>
<td>Social</td>
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<td></td>
<td>Community</td>
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<td></td>
<td>Belonging Score</td>
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<td>Total Becoming</td>
<td>Practical</td>
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<tr>
<td></td>
<td>Leisure</td>
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</tr>
<tr>
<td></td>
<td>Growth</td>
<td>-1.60</td>
</tr>
<tr>
<td></td>
<td>Becoming Score</td>
<td></td>
</tr>
<tr>
<td>Total QOL</td>
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<td>0.89</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Decision Making (+1 to +5)</th>
<th>Opportunity (+1 to +5)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td></td>
<td>3.0</td>
</tr>
</tbody>
</table>

As the table shows, Leanne assigned Naomi a Total QOL score of 0.89, falling just within the “adequate” QOL range. Naomi’s score was somewhat lower than the group mean score (2.17); four participants received higher Total QOL scores. Naomi’s Social Belonging (“the people around me”) score of 4.18 was considerably higher than her Total QOL score.
The score indicates that, in Leanne’s opinion, Naomi enjoys generally satisfactory relationships with the people in her life.

On the other hand, Naomi’s Growth Becoming (“things I do to improve myself”) score of -1.60 was notably lower than her Total QOL score. The scores suggest that, from Leanne’s perspective, Naomi lacks either the opportunity and/or personal capacity to pursue avenues of personal development. Her Decision Making and Opportunities scores (1.0 and 3.0, respectively) suggest that while Naomi has “some opportunities” to explore important areas of life she has “almost no control” over whether any type of exploration will occur.

*Naomi’s Past and Current Communication*

Naomi currently communicates using speech (fewer than 10 words), vocalizations, gestures, and a communication book with picture symbols. Leanne reported that Naomi was “satisfied” with the Alpha Talker (a voice output communication aid) that she received from SET-BC when she was in high school. She reported that Naomi did not take the communication device with her when she left school.

*Naomi’s Communication Survey Scores*

Table 3.14 displays Naomi’s *Communication Survey* scores.
Table 3.14

*Naomi's Communication Importance and Satisfaction Scores*

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score (1-5)</th>
<th>Satisfaction Score (1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>3.71</td>
<td>2.17</td>
</tr>
<tr>
<td>People</td>
<td>2.71</td>
<td>2.00</td>
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<tr>
<td>Places</td>
<td>4.00</td>
<td>2.50</td>
</tr>
<tr>
<td>Functions</td>
<td>4.42</td>
<td>2.00</td>
</tr>
</tbody>
</table>

Five participants achieved higher Total Importance scores than Naomi and three achieved higher Total Satisfaction scores. Her Total Importance score of 3.71 was just below the group mean score (3.98). Her Total Satisfaction score of 2.17 was also just below the group mean score (2.24). The table shows some variation across Naomi’s Importance scores. Specifically, Naomi’s Places and Functions Communication Importance scores (4.00 and 4.42, respectively) indicate that, in Leanne’s opinion, communicating in specific places and for purposes of daily living are “very important” for Naomi. Her People Communication Importance score (2.71) indicates that Leanne believes that communicating with people is somewhat less important for her daughter. Naomi’s Satisfaction scores, however, are consistent across the board, each falling within the “not very satisfied” range. Altogether, these scores suggest that, from Leanne’s perspective, Naomi is more disappointed with her communication in specific places and for purposes of daily living than with her communication with people.
Ursula’s Story

Who is Ursula?

Ursula is 22 years, has cerebral palsy and severe hearing and vision impairments. She lives in a small town on the Sunshine Coast with her mother, father, and sister. Ursula currently communicates through gestures and vocalizations. Ursula’s family described her as a woman who likes to be with other people and to be included in family life. She was asked to participate in the study because she received a Big Mack communication device from SET-BC when she was in high school. Ursula’s mother, Elaine, completed the Communication Survey and the QOLP-PD on Ursula’s behalf. An interview was conducted in Ursula’s family home but she was not able to answer any of the interview questions. Elaine and Ursula’s father, Fredric, and her primary support worker, Sara, answered the questions on her behalf.

Ursula’s School Career

Elaine explained that Ursula began her school career in a special education school in Winnipeg. After moving with her family to the Sunshine Coast she attended the elementary school and high school in her local community. Ursula’s parents felt that the special education school in Winnipeg was superb because it focused on goals that were meaningful for Ursula (e.g., life skills). On the other hand, Elaine described Ursula’s time in her local schools as useless: it wasn’t a successful experience at all. In her opinion, one of the worst things was that [Ursula] was one of the first severely handicapped kids in the school and they were trying all of this integration which does not work with these severely handicapped children. So, if she sat quietly through French the teachers were pleased, whereas I would be pleased if she learned to pull up her pants or go to the toilet! Elaine explained that Ursula...
experienced a lot of stress in school as a result of being expected to engage in tasks and activities that were meaningless to her.

Staffing issues were another drawback of the local school system. As Fredric put it, *we had a couple of aides at the school that were good but the rest were hopeless...and, the aides only stayed with Ursula for six months [and] she really needs consistency.* Moreover, Ursula’s teachers and aides could not respond to the fact that, as Elaine put it, *different children require different spectrums of teaching.* In other words, Ursula did not receive the specialized instruction she required. Elaine recalled how *they tried to teach her speech by showing her little dinky toys and making her say ‘car.’ But I don’t think she associates that to a car outside. To me the teaching wasn’t really doing anything.* Elaine and Fredric concluded that Ursula’s time in her local schools was, on the whole, *a hardship.* Not surprisingly, they felt that school did not prepare Ursula for adult life.

*Ursula’s Post-School Life*

As mentioned above, Ursula lives with her parents and her sister. Ursula requires assistance for all activities and receives this support from her family and Sara (who works with Ursula during the daytime, approximately forty hours per week). Sara supports Ursula to engage in her preferred activities including going to restaurants, for walks, to the beach, and to movies. Ursula attends an adult day program operated by a local *handicapped society* on an intermittent basis (e.g., 10 to 20 hours per week) where she participates in music therapy group sessions and other social activities. She also goes swimming with her family on Saturdays and to church on Sunday. Her parents reported that, above all, Ursula loves to be with people, at home or in the community. Elaine and Sara commented that just being with people, *listening to their voices,* is one of Ursula’s preferred activities. As Elaine noted,
this is one of her favourite things: when we are all here and she has her sister and family and the dog and the cat. Sara further noted that Ursula loves to be included in things: she really likes to be doing the same as other people, or she wants to do the same thing as me or have the same thing.

Ursula’s parents reported that her post-school life is considerably better than her life was when she was in school. Fredric noted: the majority of the time she is happy. Elaine continued: the difference is that the school program revolved around the other children and the aides; now I would say the program revolves around Ursula. Now the things she does are things she likes. Elaine reported that there had been a significant reduction in Ursula’s challenging behaviour since Sara began supporting her. Indeed, Elaine and Fredric credited Sara’s ability to understand and connect with Ursula as being a primary reason for the improvements in their daughter’s happiness and behaviour. Sara added, I think that [in the past few years] Ursula has learned to fit into the community, to have more community inclusion. Her behaviour is modified so that she can be in the community without being a hazard.

Elaine and Sara described some of the negative consequences of Ursula’s hazardous behaviours. For example, Ursula’s pattern of banging on the windows of moving vehicles resulted in her being banned from public transit and the high school bus. A bigger problem, however, stems from the fact that members of the community often misinterpret Ursula’s behaviours. Sara explained that Ursula enjoys swinging her body back and forth when she is being pushed in her wheelchair. She went on to report a recent incident in which Ursula had been doing this behaviour to the point of hunching over in laughter. A local physiotherapist, who happened to be driving by, pulled over and said: ‘that’s terrible! She shouldn’t be
sitting like that in that wheelchair.' She didn't understand that I couldn't stop [Ursula].

Elaine was clearly exasperated by the story and described several similar instances and sarcastically concluded that everyone knows better than you.

Elaine identified three areas of Ursula's life which she would like to see improve. The first was that she doesn't have very much that she can do at home. There is not a lot and she is not watching TV so much now. Not that she is here a lot, but we have to take her out. The second was Ursula's toileting. We are having a lot of trouble with this...it's a nightmare. Third, Elaine noted: one of the things I feel sorry for is that Ursula doesn't have a choice in anything. Elaine linked this problem to Ursula's easy-going nature and to her lack of communication skills (see Ursula's Past and Current Communication below). Sara commented that the main improvement she would like to see is for Ursula to have an easier time leaving her preferred activities: we will be coming home and she won't want to leave because she is having so much fun. Sara explained that, at times like these, Ursula is likely to fall to the floor and refuse to get up, scream, and/or bang car windows.

**Ursula's QOLP-PD Scores**

Table 3.15 displays Ursula's scores from the QOLP-PD.
Table 3.15

*Ursula’s QOLP-PD Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-Domain</th>
<th>Score (-10 to +10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Being</td>
<td></td>
<td>-0.36</td>
</tr>
<tr>
<td></td>
<td>Physical Being</td>
<td>0.18</td>
</tr>
<tr>
<td></td>
<td>Psychological Being</td>
<td>-1.00</td>
</tr>
<tr>
<td></td>
<td>Spiritual Being</td>
<td>-0.27</td>
</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td>2.00</td>
</tr>
<tr>
<td></td>
<td>Physical Belonging</td>
<td>3.20</td>
</tr>
<tr>
<td></td>
<td>Social Belonging</td>
<td>1.70</td>
</tr>
<tr>
<td></td>
<td>Community Belonging</td>
<td>1.10</td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td>-0.30</td>
</tr>
<tr>
<td></td>
<td>Practical Becoming</td>
<td>-1.00</td>
</tr>
<tr>
<td></td>
<td>Leisure Becoming</td>
<td>2.08</td>
</tr>
<tr>
<td></td>
<td>Growth Becoming</td>
<td>-2.00</td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td>0.24</td>
</tr>
</tbody>
</table>

| Decision Making (+1 to +5) | 1.0 |
| Opportunities (+1 to +5)   | 1.0 |

Elaine assigned Ursula a Total QOL score of 0.24, just within the “adequate QOL” range. The score was somewhat lower than the group mean score (2.17) and was the 2nd lowest score in the group. Ursula’s Total QOL score seems somewhat incongruent with her parent’s sense that Ursula’s life is generally positive. On the other hand, some of Ursula’s
sub-domain scores reflect specific details provided by her parents in the interview. For example, Ursula’s Leisure Becoming score (2.85) is consistent with Elaine’s comments that, on the one hand, Ursula enjoys a number of community-based recreational activities but, on the other hand, *has little to do at home*. The fact that Ursula does little at home, does not go to school, and does not engage in vocational activities is consistent with her “poor” scores in Practical Becoming (“the daily things I do”) (-1.00) and Growth Becoming (“the things I do to improve myself”) (-2.00). Furthermore, Ursula’s “poor” Psychological Being score (-2.00) makes sense in light of Sara’s comments about the way Ursula expresses her frustrations when asked to leave preferred activities. On the positive side, Ursula’s Physical Belonging (“where I live and spend my time”) score (3.20) and Social Belonging (“the people around me”) score (1.70) were notably higher than her Total QOL score. These scores reflect the fact that Ursula lives in a comfortable and safe home and is surrounded by people she loves.

Finally, Ursula’s Decision Making and Opportunities scores indicated that she had “almost no control” over important areas of her life and had “no opportunities” to make changes in those areas. These scores are highly consistent with Elaine’s regrets regarding Ursula’s opportunities for making choices.

*Ursula’s Past and Current Communication*

As noted above, Ursula currently communicates using gestures and vocalizations and received a Big Mack (a single-switch voice output communication aid) from SET-BC when she was in high school. Elaine reported that Ursula played with the Big Mack but did not effectively communicate with it. Her parents concluded that Ursula’s communication abilities are the same now as they were before she received speech and AAC services at school.
Elaine observed that Ursula’s receptive communication is limited to simple instructions (if you say ‘toilet’ she knows she is going to the toilet). Sara commented that Ursula understands what she wants her to do by picking up on my body language and from the context. For example, Ursula knows that she is going swimming when Sara presents her with her swimsuit; or, if other people are sitting down for a drink, Ursula is likely go to the kitchen and obtain a glass for herself. Sara commented that she occasionally shows Ursula photographs of upcoming activities to help her prepare for those activities: If we’re going to get her hair cut, I’ll show her a picture of her getting her hair cut at the hairdressers.

Ursula’s expresses herself primarily through non-verbal means. Sara commented that Ursula is a very good [communicator] for someone who can’t talk. She is very good at getting her needs met. Fredric reported that if Ursula is pleased with what she is doing or what is going on around her she generally shows her approval by remaining silent. For example, if Ursula is presented with two kinds of drinks, she will take the first drink you give her. She doesn’t choose. Elaine described some of the ways Ursula protests if she is expected to do something she does not want to do. Well, she screams and will bang the window or the wall. And she cries.

Ursula’s Communication Survey Scores

Table 3.16 displays Ursula’s scores from the Communication Survey.
Table 3.16

Ursula’s Communication Importance and Satisfaction Scores

<table>
<thead>
<tr>
<th>Communication Area</th>
<th>Importance Score</th>
<th>Satisfaction Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1-5)</td>
<td>(1-5)</td>
</tr>
<tr>
<td>Total</td>
<td>2.48</td>
<td>2.01</td>
</tr>
<tr>
<td>People</td>
<td>2.85</td>
<td>1.71</td>
</tr>
<tr>
<td>Places</td>
<td>1.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Functions</td>
<td>3.60</td>
<td>1.33</td>
</tr>
</tbody>
</table>

Six participants achieved higher Total Importance scores than Ursula and four achieved higher Total Satisfaction scores. While her Total Importance score of 2.48 was considerably lower than the group mean score (3.98), her Total Satisfaction score of 2.01 was only slightly lower than the group mean (2.24). There was considerable variation across the Importance scores Elaine assigned to Ursula. The difference between Ursula’s Places Importance score (1.00) and her People Importance score (2.85) reflects Elaine’s comments that Ursula is more concerned with the people around her than the environment around her. For example, Elaine observed that Ursula likes going to church on Sunday to be part of the family, but is not particularly interested in the service. On the other hand, Ursula’s Functions Importance score of 3.60—indicating that she is very concerned with communicating for her everyday wants and needs—is consistent with her reputation as being an insistent communicator, especially concerning things she does and does not want to do (e.g., use challenging behaviour to express that she does not want preferred activities to end).

Ursula’s Satisfaction scores are also marked by considerable variation. Her Places Satisfaction score of 3.00—indicating that Elaine believes that Ursula is satisfied with her
communication in the places she frequents—is understandable in the light of Ursula’s reported indifference to participating directly in the activities around her (i.e., she is not interested in communicating at church, so she is satisfied with how she does communicate there). Ursula’ Functions Satisfaction score of 1.33—indicating that she is not very satisfied with her communication for her everyday wants and needs—is consistent with comments made in the interview regarding her passive acceptance of things given to her and her frustrations arising from being denied desired activities or items. Indeed, the foregoing picture of Ursula depicts a woman who is, on the one hand, at her best when with her favourite people in her favourite places, but, on the other hand, struggles when she has to leave these people and places. Perhaps Ursula’s low Total QOL score reflects this ongoing clash between the positive and negative.

**Question for Correlational Analysis**

**Question #4:** What is the relationship between the participants’ QOLP-PD scores and their communication Satisfaction scores from the Communication Survey?

**Hypothesis:** Based on Lund (2001), there will be a positive correlation between participants’ QOLP-PD scores and their communication satisfaction scores.

**Results:** A Spearman’s rank-order correlation was calculated to examine the relationships between QOLP-PD scores (i.e., Total QOL, Being, Belonging, and Becoming scores) and communication Satisfaction scores from the Communication Survey (i.e., Total, People, Places, and Functions communication scores). Table 3.21 displays the results of the calculations and confirms the hypothesis that there
will be a positive correlation between QOL scores and communication Satisfaction ratings.
Table 3.17

*QOLP-PD scores and Communication Satisfaction Scores Correlations*

<table>
<thead>
<tr>
<th></th>
<th>Total QOL</th>
<th>Total Being</th>
<th>Total Belonging</th>
<th>Total Becoming</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>rho = .810*</td>
<td>rho = .619</td>
<td>rho = .833*</td>
<td>rho = .929**</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People</td>
<td>rho = .927**</td>
<td>rho = .805*</td>
<td>rho = .927**</td>
<td>rho = .805*</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Places</td>
<td>rho = .594</td>
<td>rho = .461</td>
<td>rho = .655</td>
<td>rho = .788*</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functions</td>
<td>rho = .934**</td>
<td>rho = .850**</td>
<td>rho = .862**</td>
<td>rho = .874**</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**p < .01 (2-tailed)  
*p < .05 (2-tailed)**

The table shows that significant correlations were found between Total QOL scores and Communication Satisfaction (CS) scores in all but one communication area. Significant correlations were found between Total Being and CS scores in two of four communication areas, Total Belonging and CS scores in all but one communication area, and Total Becoming and all communication areas. On the whole, the correlational analysis provides evidence that the participants who enjoy higher QOL scores also enjoy a higher degree of communication satisfaction. This pattern is also visually discernible in Table 3.22 which displays the participants’ Total QOL scores, Total CS scores, and Total QOL rankings and CS rankings (previously, participants were displayed in alphabetical order).
Table 3.18

Participants’ Total QOL Scores, Total Communication Satisfaction Scores, and Total QOL and Total Communication Satisfaction Rankings

<table>
<thead>
<tr>
<th>Participant by Total QOL Ranking</th>
<th>Total QOL Score</th>
<th>Total Communication Satisfaction Score and Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cindy</td>
<td>7.47</td>
<td>2.92 (2)</td>
</tr>
<tr>
<td>2. Kerry</td>
<td>7.05</td>
<td>3.71 (1)</td>
</tr>
<tr>
<td>3. Dianne</td>
<td>2.36</td>
<td>2.00 (6)</td>
</tr>
<tr>
<td>4. Jeremy</td>
<td>2.31</td>
<td>2.35 (3)</td>
</tr>
<tr>
<td>5. Naomi</td>
<td>0.89</td>
<td>2.16 (4)</td>
</tr>
<tr>
<td>7. Amy</td>
<td>0.36</td>
<td>1.73 (7)</td>
</tr>
<tr>
<td>6. Ursula</td>
<td>0.22</td>
<td>2.01 (5)</td>
</tr>
<tr>
<td>8. Jason</td>
<td>-3.03</td>
<td>1.00 (8)</td>
</tr>
<tr>
<td>mean=</td>
<td>2.17</td>
<td>2.24</td>
</tr>
</tbody>
</table>

Specifically, the table shows that the participants who achieved the two highest Total QOL scores, Cindy and Kerry, also achieved the two highest Total Communication Satisfaction scores. Along similar lines, the participant who achieved the lowest Total QOL score, Jason, also achieved the lowest Total Communication Satisfaction scores. The obvious exceptions to this trend are Dianne who, despite achieving the third highest Total QOL score only achieved the sixth highest Total Communication Satisfaction score, and Ursula who, despite achieving the seventh highest Total QOL score achieved the fifth highest Total
Communication Satisfaction score. Nonetheless, the trend displayed in Table 3.21 is
generally consistent with the results of the correlational analysis displayed in Table 3.22.
CHAPTER 4

Discussion

The goal of this research was to describe the post-school quality of life of individuals with complex communication needs who received communication technologies from SET-BC while in school. Information regarding the eight participants’ school careers, past and current communication, and outcomes in important life domains was collected via the Communication Survey. The participants’ current quality of life was measured using the Quality of Life Profile: Individuals with Physical and Sensory Disabilities (QOLP-PD, Renwick et al., 1998). Interviews with four participants were conducted to gain further understanding of the positive and negative aspects of their school career and current life circumstances. The findings of the research are discussed within the following three sections: (1) Explanation of Findings, (2) Implications (3) Integration of Findings with Past Literature, (4) Study Limitations; (5) Future Directions, and (6) Conclusions.

Explanation of Findings

Table 4.1 summarizes the participants’ QOLP-PD scores and Total Communication Satisfaction scores.
Table 4.1: Participants' QOLP-PD and Total Communication Satisfaction Scores by Total QOL Rankings

<table>
<thead>
<tr>
<th>Scores</th>
<th>Cindy #1</th>
<th>Kerry #2</th>
<th>Dianne #3</th>
<th>Jeremy #4</th>
<th>Naomi #5</th>
<th>Amy #6</th>
<th>Ursula #7</th>
<th>Jason #8</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Communication</td>
<td>2.92</td>
<td>3.71</td>
<td>2.00</td>
<td>2.36</td>
<td>2.17</td>
<td>1.73</td>
<td>2.01</td>
<td>1.00</td>
<td>2.24</td>
</tr>
<tr>
<td>Total QOL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Belonging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Belonging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Belonging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Belonging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Becoming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical Becoming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure Becoming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Growth Becoming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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As Table 4.1 shows, four participants—Cindy, Kerry, Dianne, and Jeremy—consistently achieved Total QOL and sub-domain scores above the group means in those areas. The remaining four participants—Naomi, Amy, Ursula, and Jason—consistently achieved Total QOL and sub-domain scores below the group means. The participants can therefore be divided into two groups: an “above the mean” group and a “below the mean” group. In the sections that follow, potential explanations for this result will be explored and discussed.

*Communication Satisfaction*

Again, the participants' Total Satisfaction scores are summarized in Table 4.1. Given the strong correlation reported in the previous chapter between Total QOL scores and Total Communication Satisfaction scores, it appears that communication satisfaction is the most obvious factor differentiating the “above” group from the “below” group. Indeed, three of the four participants in the “above” group—Cindy, Kerry, and Jeremy—not only achieved the three highest Total Communication Satisfaction scores but were also the only participants to achieve Satisfaction scores above the group mean score in that area. Of course, it should be remembered that, of all the participants, only Kerry's and Cindy's scores indicated that they were *more than* satisfied with their communication; Jeremy's scores indicate that he deemed his communication passable at best. These points, together with the fact Dianne achieved only the sixth highest Total Communication Satisfaction score, raise the possibility that additional factors may explain the division between the two groups. Of course, it is possible that the division can be accounted for more thoroughly on the basis of other variables that were not captured in the course of the study. Nonetheless, an attempt must be made to
consider rival explanatory hypothesis on the basis of the available data—the remainder of this section constitutes such an attempt.

School Experiences and SET-BC Supports

Findings regarding the participants’ school careers and SET-BC supports are summarized in Table 4.2.
Table 4.2

*Participants' School Career Information and SET-BC Supports*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Educational program</th>
<th>Amount of education received</th>
<th>SET-BC technology prepared for adult life by age school?</th>
<th>Prepared satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>Partly in regular classes</td>
<td>Completed high school</td>
<td>Not very satisfied</td>
<td>Yes</td>
</tr>
<tr>
<td>Cindy</td>
<td>Partly in regular classes</td>
<td>Completed high school</td>
<td>Satisfied Not sure</td>
<td>18</td>
</tr>
<tr>
<td>Dianne</td>
<td>Mostly in resource rooms, special classes</td>
<td>Completed high school</td>
<td>Not very satisfied</td>
<td>No</td>
</tr>
<tr>
<td>Jason</td>
<td>Partly in regular classes</td>
<td>Completed high school</td>
<td>Not very satisfied</td>
<td>No</td>
</tr>
<tr>
<td>Jeremy</td>
<td>Mostly in resource rooms, special classes</td>
<td>Completed high school</td>
<td>Very</td>
<td>No</td>
</tr>
<tr>
<td>Kerry</td>
<td>Partly in regular classes</td>
<td>Completed high school</td>
<td>Very</td>
<td>No</td>
</tr>
<tr>
<td>Naomi</td>
<td>Mostly in resource rooms, special classes</td>
<td>Completed high school</td>
<td>Satisfied</td>
<td>No</td>
</tr>
<tr>
<td>Ursula</td>
<td>Mostly in resource rooms, special classes</td>
<td>Completed high school</td>
<td>Not very satisfied</td>
<td>No</td>
</tr>
</tbody>
</table>
As the table shows, all of the participants or their informants reported that they (a) received their education primarily in special education settings, (b) generally believed that they were not prepared for life beyond the classroom, and (c) did not meet the requirements for a Dogwood Certificate. Given the homogeneity of the participants’ school careers, it appears the “above the mean” and “below the mean” division cannot be explained on the basis of educational experiences or achievements.

On the other hand, three of the four participants who were satisfied or very satisfied with the communication technology they received from SET-BC—Cindy, Kerry, and Jeremy—were members of the “above the mean” group. Naomi was the only other participant who was satisfied with her technology; while Dianne, the remaining member of the “above the mean” group, was said to be not very satisfied. Interestingly, all of the participants who reported not being satisfied with their technology had an autism spectrum disorder (ASD) and/or intellectual disability (Dianne had Rett Syndrome, a degenerative disorder on the autism spectrum characterized by intellectual disability as well specific physical challenges; Naomi was reported to have an intellectual disability without secondary diagnoses). Cindy, Kerry, and Jeremy, on the other hand, all had cerebral palsy (Cindy also had an intellectual disability). Perhaps, the “disability-satisfaction” relationship is a reflection of SET-BC’s expertise and resources: that is, perhaps this program is more equipped to serve individuals exhibiting the features of cerebral palsy than those with ASD. Indeed, a common theme in the interviews concerned the fact that SET-BC and school staff struggled to provide appropriate technology and/or design interventions suited to the participants’ unique needs or abilities. Such complaints were registered in the interviews with Amy, Dianne, and Ursula and their family members, each of whom had autism and/or an intellectual disability (e.g.,
Bill and Deborah reported that Amy did not understand the symbol set chosen for her communication device; Elaine and Frank reported that Ursula regarded her Big Mac device as a toy). The suggestion that SET-BC possessed greater expertise for providing services to individuals with cerebral palsy than other disabilities was expressed most forcibly by Janet, Dianne’s mother: *SET-BC got involved with [Dianne] when they first started to do the CP students, and that’s who they were really interested in.*

Although this potential disability-satisfaction relationship provides limited insight into the participants’ *current* lives and QOL, it raises the possibility that the group division can be accounted for on the basis of services and supports received by the two groups. Because all the participants reported requiring support for all activities, the potential impact of services and supports on their post-school lives cannot be underestimated. The participants’ Community Belonging (“my access to resources”) scores indicated a pervasive dissatisfaction with the services and supports available to them. This dissatisfaction is exemplified by the Community Belonging group mean score (0.07), which was the lowest mean score for all of the sub-domains. As noted previously, family members repeatedly complained about the lack of resources available to individuals with disabilities; Susan spoke for many of the parents when she characterized adult services in the province as a *black hole.* They typically identified a need for services and supports to (1) increase participants’ opportunities to engage in community-based activities (e.g., vocational and/or recreational activities) and (2) enhance participants’ communicative capacities (through AAC/speech-language pathology services and resources).

*Post-School Educational, Vocational, and Recreational Supports*

Table 4.3 summarizes important aspects of the participants’ post-school lives.
### Table 4.3

**Participants' Post-School Outcomes and Information**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Years out of school</th>
<th>Living Circumstances</th>
<th>Vocational/Daytime Activities</th>
<th>Recreational Activities (# of)</th>
<th>Support required for...</th>
<th>Currently using SET-BC aid?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>5</td>
<td>Group home</td>
<td>Volunteer work; Day program</td>
<td>6</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Cindy</td>
<td>3</td>
<td>Family home</td>
<td>Volunteer work; Day program</td>
<td>5</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Dianne</td>
<td>3</td>
<td>Own apartment</td>
<td>Volunteer work</td>
<td>6</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Jason</td>
<td>1</td>
<td>Family home</td>
<td>Day program</td>
<td>1</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Jeremy</td>
<td>3</td>
<td>Family home</td>
<td>--</td>
<td>3</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Kerry</td>
<td>4</td>
<td>Family home</td>
<td>--</td>
<td>6</td>
<td>All activities</td>
<td>Yes</td>
</tr>
<tr>
<td>Naomi</td>
<td>4</td>
<td>Group home</td>
<td>Sheltered workshop</td>
<td>4</td>
<td>All activities</td>
<td>No</td>
</tr>
<tr>
<td>Ursula</td>
<td>3</td>
<td>Family home</td>
<td>Day Program</td>
<td>4</td>
<td>All activities</td>
<td>No</td>
</tr>
</tbody>
</table>
Three types of community-based activities were available to participants after they left school: educational, vocational, and recreational. The participants' educational and vocational outcomes were not encouraging. While the literature suggests that individuals with complex communication needs are quite able to obtain employment or receive post-secondary education (e.g., Huer, 1991; Light, Stoltz, & McNaughton, 1996; Lund, 2001; Odom & Upthegrove, 1991; Slesaransky-Poe, 1997), none of the participants in the present study reported involvement in either domain. Indeed, as Table 4.3 shows, only four of the participants reported involvement in any type of “productive” daytime activities—Cindy, Amy, and Dianne volunteered (on a part-time basis, i.e., once a week) while Naomi worked in a sheltered workshop. Otherwise, four participants—Cindy, Amy, Ursula, and Jason—attended day programs operated by adult service agencies while Kerry and Jeremy reported no involvement in vocational or educational activities at all. Overall, the four “below the mean” participants—Amy, Jason, Naomi, and Ursula—appeared to receive slightly more services and supports for vocational and community-based activities than their “above the mean” counterparts. On the other hand, the “above the mean” group reported regular involvement in a marginally higher number of recreational activities (i.e., three members of the “above the mean” group participated in at least five activities per week while only one member of the “below the mean” group participated in the same number). These numbers suggest that the members of “above the mean” group received slightly more supports for recreational activities than their counterparts. On the whole, however, it appears that the two groups cannot be distinguished on the basis of the number of services or supports received in the context of educational, vocational, community-based, or recreational activities.
Post-School Communication Supports

Table 4.4 summarizes the communication modes currently used by the participants.

Table 4.4: Participants’ Current Communication Modes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Current Communication Modes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>Manual signs, gestures, communication book, vocalizations</td>
</tr>
<tr>
<td>Cindy</td>
<td>Communication book, gestures, and vocalizations</td>
</tr>
<tr>
<td>Dianne</td>
<td>Blink-and-eye-gaze system, gestures, vocalizations</td>
</tr>
<tr>
<td>Jeremy</td>
<td>Gestures, vocalizations</td>
</tr>
<tr>
<td>Jason</td>
<td>Gestures, vocalizations, speech (less than 10 words)</td>
</tr>
<tr>
<td>Kerry</td>
<td>Eye gaze system (with written communication book), personal computer (for writing)</td>
</tr>
<tr>
<td>Naomi</td>
<td>Speech (under 10 words), communication book, gestures, vocalizations</td>
</tr>
<tr>
<td>Ursula</td>
<td>Gestures, vocalizations</td>
</tr>
</tbody>
</table>

Regardless of group, the participants and their families consistently lamented the lack of AAC/communication services for adults with disabilities in the province. One illustration of this predicament is the fact that Cindy was the only participant who had received a communication aid from a government-funded adult service provider (i.e., a local rehabilitation hospital). Otherwise, the participants who used aided AAC—in this case, communication books—received their aids from their families (i.e., Amy, Dianne, Kerry, and Naomi). While this finding shows that the most valuable AAC supports came from families, family members consistently argued that further expertise and resources were necessary to
maximize the participants' communicative capacities. For instance, Janet admitted that, while she was in a position to independently purchase a communication device for Dianne, a number of obstacles prohibited her from doing so. These obstacles included (a) her limited knowledge regarding the kinds of communication devices which would accommodate Dianne's needs and abilities and (b) her lack of expertise in supporting Dianne's successful use of such a device. Similarly, Cindy and her mother Joyce noted their intention to purchase a voice-output communication aid (VOCA) but also stated their desire to receive post-school follow-up services from SET-BC or an analogous AAC organization. These points serve as a reminder that enhancing an individual's communicative competence through AAC involves much more than the providing that individual specific pieces of equipment or technology. Rather, AAC intervention is a dynamic process which, at the very least, involves supporting the individual to maximize the efficiency and effectiveness of his or her total communication system through the development and integration of various strategies, techniques, symbols, as well as specific aids. Janet's and Joyce's comments in the survey reflect the need for a certain level of expertise to support the ongoing process of AAC intervention. While the families in the study supported the participants to the best of their abilities, they clearly believed that their efforts needed to be bolstered by sustained professional involvement.

Communicative Competence

The foregoing observations suggest that the "above the mean" group cannot be distinguished from the "below the mean" group on the basis of AAC/communication services and supports received after leaving secondary school, since none of the participants received such supports. On the other hand, a variety of data sources suggest that the "above the mean" group enjoyed a higher degree of communicative competence than their counterparts. Light
observed that “the attainment of communicative competence by individuals who use AAC requires a complex interplay of knowledge, judgement, and skills across four domains: linguistic, operational, social, and strategic” (Light, 2003, p. 5). It is possible to see the role that at least some of these competencies played in the communication abilities of the participants. For instance, in order for them to complete the surveys and participate in the interview process—that is, in order to understand and respond to questions regarding personal thoughts and feelings—Cindy, Kerry, and Dianne had to possess a relatively high level of linguistic competence. Linguistic competence refers to a person’s ability to (a) comprehend the spoken language of her community and (b) express herself in that language using the AAC codes and symbols at her disposal. In contrast, operational competence “refers to skills [used] in the technical production [i.e., production of symbols] and operation of AAC systems” (p. 11). Carol’s comments regarding Kerry’s mastery of her eye gaze system indicate that she has achieved operational competence with that system (i.e., she is able to reproduce the eye movements needed to locate specific messages in her communication book without the book being present). Similarly, Dianne demonstrated a high degree of operational competence with her blink-and-eye-gaze system during her interview (e.g., she produced clear ‘yes’ blinks at the appropriate moments). Moreover, Dianne and Janet had developed a number of strategies designed to compensate for some of the linguistic constraints placed on Dianne by her two primary communication modes. These strategies included Janet’s training of Dianne’s support staff to understand her non-verbal behaviours and to re-phrase open-ended questions as ‘yes/no’ questions. This kind of strategic competence—i.e., that is, techniques employed by people who use AAC and/or those who support them to bypass limitations in the linguistic, operational, or social domain (Mirenda &
Bopp, 2003)—may account as well (at least in part) for Jeremy’s effectiveness as a communicator and for his relatively high communication satisfaction scores. Susan’s description of Jeremy implied that he had developed creative ways to get his messages across, despite being expressively limited to gestures and vocalizations. Of course, Jeremy also appeared to possess a high degree of receptive linguistic competence, as indicated by Susan’s report that he understands everything you say to him.

On the basis of the data collected, a similar range of communicative competencies was not evident for the “below the mean” group (Amy’s strategic use of readily available graphic-visual materials [e.g., flyers] represents the only obvious exception here). Furthermore, this group’s lack of involvement in the completion of their surveys and their interviews (at least for Amy, Jason, and Ursula) indicates that, generally speaking, their communicative abilities were not on par with those of their counterparts.

The difference between the two groups’ overall level of communicative competence appears to be the most plausible explanation of the overall difference between their Communication Satisfaction scores. It follows that individuals who are capable of entering into discussions of their life circumstances (i.e., through surveys and interviews) would be more likely to have a “voice” in the creation of those lives than individuals who are less capable of entering such a discussion. Moreover, it seems plausible that individuals with limited communicative competence would be at risk for falling into a life not of their own making, a life that is likely to be marked by deficits of satisfaction and excesses of frustration. Perhaps, this risk became something of a reality for the members of the “below the mean” group; this would certainly go a long way in explaining their lower QOL scores. Of course, given their general lack of satisfaction with their communication capacities and
modes and their relatively low QOL scores, this view could be extended to Dianne and Jeremy as well.

Implications

One obvious implication of many of the findings of this study is that concerted efforts should be made both to improve participants' abilities to communicate in daily contexts (e.g., functional and social communication) and to identify sources of their satisfactions and frustrations. On the latter point, there is a growing body of research related to self-determination that focuses on enhancing the participation of individuals with developmental disabilities in quality of life assessments and related outcome evaluation procedures (e.g., Bonham, Pisa, & Schalock, 1999; Schalock, Bonham, & Marchand, 2000; Wehmeyer & Schwartz, 1998). Ideally, advancements in this area will be increasingly incorporated into the individualized and personal planning processes of high schools and adult service providers and will help participants like those in the present study identify their satisfactions, frustrations, goals, and dreams.

Of course, on the basis of the data available, it is impossible to make specific statements regarding the kinds of strategies or techniques that might enhance the communication of the study participants in the context of their daily lives. However, many of the parents involved in this study were clear that the process of allocating AAC resources should be based on collaboration between professionals, individuals with complex communication needs (to the extent possible), and their long-term facilitators (e.g., parents). In this view, the development of an optimal communication system depends upon a sharing of expertise between those who have intimate knowledge of an individual's goals, needs, and learning style and those who have extensive knowledge of AAC techniques, technologies,
and strategies. Not surprisingly, a number of commentators have identified such collaboration as an integral part of AAC intervention (Beukelman & Mirenda, 1998; Huer & Lloyd, 1990; Lund, 2001).

A number of commentators and researchers have also stressed that both the assessment and the enhancement of quality of life is a shared, "inter-subjective" process (Klatt et al., 2002; O’Brien, 1987; Rapley, 2000). From this perspective, the process of building a life that is truly based on an individual’s subjective preferences and goals invariably requires the involvement of concerned, familiar others. O’Brien’s (1987) adage, "none of us make our lives alone" (p. 175), implies that this it true for individuals both with and without disabilities. This “person-centered” perspective of quality of life has affinities with the model of communicative competence offered by Light (2003) and others in the AAC field. The model views communicative competence as the product of a network of factors that are both intrinsic and extrinsic to the individual who uses AAC. Intrinsic factors include the competencies reviewed earlier as well as psychosocial elements such as motivation, resilience, and so forth; while extrinsic factors include the “communication demands” encountered by the individual as well as various “environmental barriers and/or supports” to AAC use (e.g., policies, available technologies) (Light, 2003, p. 5). In this view, the spontaneous act of communicating one’s ideas and feelings is revealed to be the product of planning, strategizing, and cooperating—in other words, like quality of life, it is an inescapably inter-subjective process. Future research is needed to elucidate the role played by intrinsic and extrinsic factors in the enhancement of quality of life and communicative competence for individuals with complex communication needs. The findings of the present study argue the need for individuals involved in AAC service delivery to be aware of, and
whenever possible, work in conjunction with the multiple and potentially competing perspectives surrounding individuals with complex communication needs.

*Integrations of Findings with Past Literature*

QOL studies by Lund (2001); Slesaransky-Poe (1997); and Brown, Raphael, & Renwick (1997) represent obvious reference points for the present study. While Lund’s study also featured a small sample of young individuals with complex communication needs, it departs from the present study in a number of important ways. First, all of the participants in that study had cerebral palsy without secondary diagnoses; second, all of the participants possessed sufficient communicative competence to independently complete the *QOLP-PD*; and third, all of the participants had enjoyed sustained AAC intervention and access to AAC services for most of their lives. Perhaps these factors can account for the fact that the Total QOL group mean score in that study, 4.7, was notably higher than that achieved in the present study, 2.17. Cindy and Kerry, having achieved Total QOL scores of 7.47 and 7.05 (respectively) were the only participants who could “compete” with Lund’s participants on the basis of QOL scores. On the other hand, the two participants in Lund’s study with the highest QOL scores (8.0 and 7.1) also attended college and had obtained part-time employment, neither of which applied to Cindy and Kerry. These findings exemplify the fact that the participants in Lund’s study were generally more involved in post-school activities and more satisfied with both their overall life outcomes and their communication than the participants in the present study. Questions remain regarding the degree to which these “better” outcomes can be attributed to the participants’ sustained use of AAC.

As noted previously, Slesaransky-Poe (1997) hypothesized the existence of positive correlations between communication satisfaction, QOL, and the use of VOCAs by
individuals with complex communication needs. Like the present study, Slesaransky-Poe found a positive correlation between communication satisfaction scores and QOL scores. On the other hand, she found a positive correlation between communication satisfaction scores and VOCA use. In this regard, the findings of the two studies cannot be compared: given the variety and heterogeneity of the communication modes used by the participants in the present study, it would be impossible detect a relationship between any specific communication mode and either communication satisfaction or QOL.

The Ontario QOL Project (Brown, Raphael, & Renwick, 1997) found a significant relationship between higher QOL scores and “having verbal skills” (p. 192). In the QOL Project, “having verbal skills” was defined by participants’ capacity to complete the QOL survey with a modicum of support. This finding thus corroborates the present study’s finding regarding the relationship between linguistic competence and QOL, especially for the Cindy and Kerry, the two participants who were most actively involved in survey completion. Moreover, the QOL Project found a significant relationship between higher QOL scores and “not having marked behaviour problems” (p. 192); the researchers also observed that “there were few people [in the study] who were both verbal and rated as having marked behaviour problems” (p. 80). In the present study, three of the four members of the “below the mean” group (Amy, Ursula, and Jason) were reported to engage in problem behaviour. The congruence of such findings is not surprising, especially if problem behaviour is understood as the result of breakdowns in communication (this is precisely how Bill and Deborah described Amy’s behaviour, for example).

Generally speaking, the participants in the present study and the QOL Project consistently achieved their lowest scores in the Becoming domain, particularly Growth
Becoming ("the things I do to improve myself"). In the present study, Cindy and Kerry were the only exception to this pattern, achieving scores of 9.50 and 6.54 in this domain, respectively. While the low scores in the sub-domain were not accounted for in the QOL Project, the participants in the present study, particularly those who were interviewed, evidenced a sense of being “stuck” and lacking both the resources and the opportunities to grow on a personal level (e.g., Dianne’s difficulties in expanding her activity patterns, Lisa’s sense that Jason had “dropped out” of life). Indeed, the percentage of participants involved in productive activities was much higher in the QOL Project than the present study; 75% of the participants in that study engaged in “occupational activities” (p. 38); approximately half worked in either competitive or supported employment, sheltered workshops, or volunteer positions; and about one-fifth were involved in educational or training endeavours. The remainder attended some kind of adult day program (i.e., a “developmental” or “recreational” program). These figures suggest that it is possible for Canadians with developmental disabilities to obtain work and receive further education or training. Of course, it could be argued that the discrepancy between the occupational (or vocational) outcomes of the participants in the QOL Project and those of the participants in the present study can be explained on the basis that the former group have had more time to achieve such outcomes than the latter group. However, such an explanation loses credibility given the fact that, of all the participants in the present study, only Amy (or her parents) reported that she was looking for work. Of course, it is unclear why the participants and their supporters were not interested in pursuing vocational options. Perhaps, the limited availability of services informed their lack of interest or optimism. Perhaps, the problem stems back to their school careers and the perception that they were not well-prepared for adult life there. In either case, the paucity of
vocational or educational outcomes in the present study indicate the need to continue the
endeavour of demonstrating that it is possible for individuals with complex communication
needs to graduate, work, and receive post-secondary education (Huer, 1991; Light, Stoltz, &
McNaughton, 1996; McNaughton, Light, & Arnold, 2002)—apparently, this work needs to be extended to the Canadian context.

Study Limitations

The findings of the present study are limited in three ways. First, the participants represent a small sample of volunteers drawn from a sub-set of individuals with complex communication needs who received communication technologies from SET-BC between 1998 and 2003. As a result, the sample may not be representative of the broader population of individuals with complex communication in the early years of their post-school lives. Consequently, the study’s findings have limited external validity. Hopefully, these limitations were somewhat offset by the richness of the data collected from and about the eight participants. The QOLP-PD that was used in this study is an extensive questionnaire touching upon a wide range of life domains. The information gathered from this instrument provided a detailed view of the participants’ lives. Furthermore, interviews with four of the participants and the people who know them best added invaluable depth and dimension to the survey data. In all, it is hoped that the reader’s understanding of some of the concerns and joys experienced by individuals with complex communication needs and their families will be enhanced by the singularities and commonalities contained within the eight stories developed here.

Second, the reliability of surveys or the interviews may be limited by the fact that, due to their limited communicative capacities and the nature of their disabilities, the majority
of participants relied on their parents to complete the surveys and represent them in the
interviews. Although survey package instructed parents to complete the respond to survey
items from the participant's perspectives, it is impossible to estimate the extent to which the
parents' responses truly reflected the participants' views, beliefs, and feelings. Nonetheless,
steps were taken to increase the reliability of data. First, the decision to ask parents to
complete the surveys and participate in the interviews was based on the logic that the family
members have the most in-depth, long-term knowledge of the participants' past and current
lives—they were thus deemed to be the most legitimate single source of information. (As
noted earlier, a similar logic was employed in the Ontario QOL Project where the QOL of
“non-verbal” participants was evaluated by “an individual who knew the participant very
well [and] who independently completed a QOLP-DD by taking the participant’s
perspective” [Brown et al., 1997, p. 11]). Furthermore, in cases where data points appeared
confusing or contradictory, the researcher sought clarification from family members via
telephone calls or as part of the interview process.

Third, given the important role played by communication in distinguishing the two
outcome groups, it is unfortunate that additional information regarding the participants’
communication and social lives was not collected, and that interviews could not be conducted
with all eight participants and their families. While information regarding the participants’
communication modes was collected, it was impossible to discern which modes were most
commonly used, the modes with which the participants felt most confident, and with whom
and in what contexts various modes were used. Such information would have provided a
broader picture of the relative strengths and weaknesses of the participants’ communicative
capacities as well as some of the natural supports and barriers to their communicative
interactions. For example, perhaps the absence of non-family communication partners who understood how to interpret her eye gaze acted as a barrier to Kerry in obtaining employment or further education. Conversely, perhaps the presence of familiar and skilled communication partners promoted the volunteer/work efforts of participants like Amy or Naomi. Such information would have provided a greater sense of the kinds of resources needed by the participants (e.g., instructional or technological supports).

More specific communication information would have also dovetailed nicely with a greater understanding of the participants’ relationships and social competencies. As Susan noted, in the absence of full-time employment opportunities, Dianne’s social and recreational life had become her “occupation.” Perhaps the “above the mean” group had more or closer friendships than their counterparts. Perhaps their communicative competence was indispensable in the development and maintenance of those friendships. In terms of scoring, the Social Becoming sub-domain of the QOLP-PD does not distinguish between familial and non-familial relationships—this unfortunate in light of the importance generally accorded the development of friendships between individuals with disabilities and their peers (Light, Arnold, & Clark, 2003; Roeher Institute, 1990).

**Future Directions**

The present study was designed to combine some of the strengths of previous studies by Lund (2001) and Slesaransky-Poe (1997). The QOLP-PD was chosen for use in the present study to facilitate comparisons with Lund’s study, which also sought to examine the QOL of young individuals with complex communication needs. Lund’s study was notable for its rich documentation of outcomes in a number of life domains and its use of a variety of instruments to assess the participants’ communication abilities. Unfortunately, Lund did not
explicitly show the ways in which the various findings were connected—for example, readers are left to draw their own conclusions regarding factors that may have contributed to or detracted from the participants’ QOL. Conversely, Slesaransky-Poe went to great lengths to identify specific relationships between QOL and aspects of the participants’ communication lives. Moreover, by enabling the participants to be the ultimate judges of their effectiveness as communicators—measured in terms of their satisfaction with their communication—Slesaransky-Poe’s study was consistent with contemporary “person-centered” QOL measurement procedures (Renwick et al., 2003; Taylor & Bogdan, 1990). Similarly in the present study, the *Communication Survey* (which was modeled after a survey used by Slesaransky-Poe) was designed to facilitate an understanding of the relationship between the participants’ communication satisfaction and their quality of life as measured by the *QOLP-PD*.

In retrospect, it is evident that there are a number of theoretical and empirical problems contained in Slesaransky-Poe’s work. For example, her goal of identifying a relationship between QOL and the use of specific communication devices (VOCAs) was based on the tacit logic that “if it is possible to detect a relationship between communication satisfaction and QOL, and another relationship between communication satisfaction and VOCA use, then it is reasonable to assume a relationship between QOL and VOCA use.” Again, despite numerous re-examinations of her data, Slesaransky-Poe was unable to detect a significant correlation between VOCA use and QOL. She may have been less surprised by her findings, however, had she considered that her guiding logic was not only syllogistically “shaky” but that it also clashed with two accepted “wisdoms”: (1) The concepts of communicative satisfaction, effectiveness, and competence are inter-related, making it
essential that "judgements regarding the effectiveness of AAC interventions do not rely solely on measures of device usage" (Lund, 2001, p. 3; cf. Calculator, 1988; Light, 1989, 2003); and (2) That there are both direct and indirect relationships between an individual’s communication capacities and his or her QOL (Hughes & Hwang, 1996; O’Keefe, 1996, Schalock et al., 2002; Schlosser, 2003; Taylor & Bogdan, 1990). Both of these points will be discussed in the sections that follow, with a view to identifying future directions for AAC research and practice.

*Communication is More than Device Usage*

The fact that communication is a multi-modal process makes it difficult to determine the specific factors that contribute to the success of any communicative exchange. For example, facial expressions may be important for conveying the meaning of a spoken utterance, and hand gestures may be critical for conveying the meaning of an utterance produced via a VOCA or a visual-graphic aid. However, the communicator in either case is not likely to be aware of his or her production of such non-verbal behaviours, let alone the effects of these behaviours on communication partners. Slesaransky-Poe attempted to control for this problem by asking participants to rate their "communication effectiveness" both when using and not using their VOCAs—in this way, she hoped to provide evidence that the VOCA users were more satisfied with their communication than the non-VOCA users. Of course, such a procedure assumes that the participants were aware of the totality of factors underlying their communicative effectiveness, regardless of whether or not they were using their VOCAs. Moreover, the inter-subjective nature of communication limits the extent to which a communicator can make generalizations about the effectiveness of his or her own communication: How often are any of us aware of whether or not our intentions—what we
mean to communicate—exactly match what our communication partners understand us to be communicating? For these reasons, in the present study, the term “communication satisfaction” was used rather than “communication effectiveness,” in order to emphasize the thoroughly subjective quality of these measurements.

The complex nature of communicative acts—i.e., that they typically involve more than one communication mode and that their success can only be judged by all of the parties involved—is an implicit assumption of the communicative competence model. The concept of communicative competence is more relevant and useful to AAC intervention and research than the concept of communicative effectiveness because the latter can neither be taught nor predicted. After all, an important measure of an AAC intervention is the extent to which it enables the individual to communicate in unfamiliar, unanticipated contexts with unfamiliar, unanticipated individuals. AAC interventions can thus support an individual and the people in his or her life to acquire various competencies and develop various strategies, in order to increase the likelihood that he or she will communicate successfully in unanticipated as well as routine contexts; however, intervention cannot guarantee successful exchanges or interactions. Moreover, while the importance of technology cannot be underestimated (especially for individuals like those in the present study who have little or no access to it), the model of communicative competence suggests that technology—or any other communication mode, technique, government policy, etc.—should be perceived as one part of the totality of communicative acts and contexts.

Accordingly, the model of communicative competence points to the need for multiple measures and perspectives within AAC research and intervention. Again, the strength of Lund’s study arose from her use of multiple measures. Specifically, she assessed various
features of her participants’ communicative competence using standardized measures in both traditional assessment settings and contrived, interactive contexts. She also invited the participants and their parents to discuss contextual supports and barriers to using AAC. On the other hand, she did not gather the participants’ perspectives regarding their communicative abilities nor those of individuals who knew them well. Thus, one useful addition for future research would be the collection of subjective data from both participants and their parents, as well as the perspectives of unfamiliar communication partners present in the participants’ communities. Furthermore, it would be useful to incorporate various kinds of feedback into future studies of this type. Specifically, using an instrument similar to that used by Slesaransky-Poe or the present study (i.e., *The Communication Survey*), participants could rate their perceptions of their own communicative competence before and after the completion of the various standardized communication assessments. It would be informative to document their responses to the assessment results as well as any resultant changes in their self-ratings. The procedure would follow the logic of video feedback, enabling the participants to judge their performance on the basis of external data. In short, future research would do well to evaluate the communicative competence of individuals who use AAC by combining the subjective measures used by Slesaransky-Poe and the present study with some of the objective measures used by Lund. Such procedures would be consistent with both the person-centered goals of consumer empowerment and the inter-subjective nature of communication itself.

*Relationships Between Communicative Competence and QOL*

Rather than pursuing Slesaransky-Poe’s (1997) goal of identifying factors associated with certain standards of QOL (e.g., “higher” QOL scores relative to others), future research
should seek to identify factors that appear to simply improve or add value to individuals’ QOL. This goal would be best pursued through longitudinal or pre-post intervention research. In addition, hypotheses regarding the potential effects of any type of AAC/communication enhancement intervention on QOL should consider and respect the complexities of QOL and the particular QOL model/instrumentation being used. As an example, consider the CHP QOL model, as reflected in the QOLP-PD used in this study. The majority of items on that instrument bear an “indirect” relationship to communicative acts or competence (Schlosser, 2003). Of the nine sub-domains, only Social Belonging ("the people around me") contains more than a few items which would qualify as being directly related to communication (see Appendix E). Consequently, the notion that the use of a specific kind of communication technology could have a discernible effect on the totality of an individual’s life—that is, that it could compete and “win” against the myriad of other forces in an individual’s life—is unlikely to be verified by such an instrument. These matters, which pertain partly to the sensitivity to change of QOL instruments (for which the QOLP-PD has not been evaluated [Renwick et al., 2003]) and partly to the broad relationship between communication and QOL, deserve further empirical investigation (O’Keefe, 1996).

Again, the model of communicative competence as presented by Light and others (Light, 1989, 2003) appears to offer a powerful framework for theorizing the relationship between AAC, QOL, and related life outcomes. Like a number of recent publications involving individuals with complex communication needs (Fried-Oken & Bersani, 2000; Mirenda & Bopp, 2004), the present study provided a few examples of “communicative competencies in action” (e.g., Kerry’s operational competence with her eye gaze system, Janet’s strategic training of Dianne’s support workers) and their relation to the participants’
well-being (e.g., Amy’s use of flyers to request items and cookbooks as the basis of social interaction). Future research should continue to examine the relationships between specific competencies and QOL and related outcomes.

The communicative competence model also indicates a need to continue examining the “environmental barriers and/or supports” that affect AAC intervention and communicative competence (Light, 2003, p. 5). The difficulties in obtaining AAC services experienced by the participants and their families in the present study and reported elsewhere (Schlosser & Rothschild, 1999) indicate that this need is of particular relevance in the Canadian context. In a number of the U.S. studies documented earlier, individuals who use AAC complained about their frustrations around faulty equipment and a lack of efficient repair and maintenance services—nonetheless, mere access to AAC technologies and associated resources was rarely identified as a problem (Light, Stoltz, & McNaughton, 1996; Lund, 2001; McNaughton, Light, & Arnold, 2002; McNaughton, Light, & Groszyk, 2001). In the present study, one participant’s parent was recorded as stating, You don’t teach somebody something and then take it away, referring to the fact that her daughter had received a communication device in school but was not permitted to use it upon entering adulthood. Parents were also adamant that receiving technology is only half the battle—receiving expertise and services to use that technology in a life-enhancing fashion is the other half. As one participant in Lund’s study stated: “Technology is awesome, but it doesn’t solve everything” (p. 108).

Clearly, future research is needed to address the apparent lack of AAC resources for adults with developmental disabilities in Canada. First, research is necessary to gain an understanding of the size of the problem: How many individuals with complex
communication needs live in Canada? How many receive AAC services and how many require or desire further services and supports? Such research could be modeled after demographic studies of individuals with complex communication needs who use AAC conducted in other parts of the world (e.g., Bloomberg & Johnson, 1990; Huer, 1991; Matas et al., 1985; Murphy et al., 1996). Second, it is necessary to gain an understanding of the nature of the problem: What are the political, attitudinal, and/or resource barriers to AAC intervention in Canada? What kind of political and/or educational efforts are needed to change the situation? Such research could inform the advocacy efforts of Canadians with complex communication needs and their supporters.

Conclusions

This study was designed to provide a concise description of important life outcomes of a specific group of individuals with complex communication needs. It was assumed that a cross-sectional survey design represented the ideal format to achieve this goal and to maximize the number of study participants (McMillan, 2000). It was also assumed that a wide variety of outcomes, from “poor” to “excellent” (approximating those achieved by participants in Lund’s study) would be discovered across discernible outcome “groups” (e.g., “high” to “low” achievers). These assumptions were not borne out by the data. First, a relatively small number of surveys were returned, possibly because the length of the QOLP-PD prohibited individuals and/or their guardians from completing and returning them. Second, the data collected from the participating individuals evinced what can best be described as a range of “poor” to “mediocre” outcomes, especially in the non-QOLP-PD domains. Thus, while it was possible to discern two groups within the data (i.e., the “above the mean” and “below the mean” groups), it was difficult to draw conclusions about specific
conditions that appeared to be associated with or promote positive life outcomes and achievements (i.e., in the manner of the QOL Project). Consequently, the primary lessons and implications of the study can be described as being more political than empirical, in that they suggest a strong need to advocate for the delivery of quality post-school services and supports to students and individuals with complex communication needs. Indeed, while learning about the participants' lives during data collection, it was often difficult for the researcher to remain neutral and not become saddened and frustrated by the restrictions they encountered after leaving school. Hopefully, the researcher's belief in the enormous potential of AAC and related interventions enabled him to report the participants' stories and approach the summary data both respectfully and objectively. In the end, the outcomes attest to the need for further scientific inquiry aimed at expanding the AAC evidence base, especially in Canada. Ideally, such inquiry will play a central role in much-needed advocacy efforts.
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withdraw from the study at any time, even after signing this consent form. Refusing to participate or withdrawal will not jeopardize (student’s name) current or future relationship with the University of British Columbia or SET-BC.

Please indicate on the form provided on the attached page whether or not (student’s name) will participate in the study. Please sign and date the form and return it in the enclosed stamped, self-addressed envelope by (Date), whether or not (student’s name) has decided to participate in the study. If (student’s name) will participate, please return the completed surveys as well.

Thank you very much for considering this request.

Sincerely,

Bruce Hamm
Appendix C

LOTTERY ENTRY FORM

To enter the lottery for a $100.00 gift certificate to a local restaurant or bookstore of your choice, please complete this form, place it in the small envelope, seal it, and return it with the completed questionnaires in the enclosed large, stamped self-addressed envelope. Except for the winning form, all forms will be destroyed without being opened after the lottery.

Name: ____________________________________________________________

Address: __________________________________________________________

____________________________________________________________________

Phone number or email: ____________________________________________
PLEASE COMPLETE THIS SURVEY FIRST!

This survey is for individuals who received communication technology from SET-BC when they were in school. Its purpose is to find out who you are, what you have been doing since you left school, and how satisfied you are with current abilities to communicate.

The survey consists of three sections:

1) Information About Yourself,
2) Your Communication, and
3) Survey Help

Instructions at the beginning of each section will tell you how to complete them.

We appreciate your taking the time to complete this survey. It should take you about 30 minutes to complete.

AFTER you have completed this survey, please complete the “Quality of Life Profile: People with Physical and Sensory Disabilities.”
Section 1. Information About Yourself

In this section you are asked questions about who you are and what you do, etc.

INSTRUCTIONS:

► Read the questions carefully or have someone read them to you. Then, write in your answer or check the box ☑ that matches your answer, OR, have someone write your answers in or check the box for you.

► It is very important that the answers given in this survey are the answers of the person who used communication technology from SET-BC when they were in school. It is okay if someone helps the person to complete the questionnaire.

► If the person cannot answer some or all of the questions directly, the helper must do everything possible to answer the questions from the person’s perspective.

► For most of the questions, you will check only one box. If none of the boxes match your answer, check either the “OTHER” box or the “None of the above” box. If you check “OTHER” you will be asked to write your answer on the line provided. Please write as much as you need.

► Some questions will ask you to “check all that apply”—these are the only questions where you may check more than one box.

► Some questions ask you to rate your satisfaction with a type of communication technology you used or currently use. You will rate your satisfaction on a scale of 1 to 5, using the rating scale below the question.
1) Code Number: ____________________________

2) Today's Date: month: _____ day: _____ year: __________

3) Date of your birth: month: _____ day: _____ year: __________

4) City or town where you live: ____________________________

5) What is your gender?
   □ Female □ Male

6) What is the primary language you speak at home?
   ____________________________________________________________

7) What is your disability? (check all that apply)
   □ cerebral palsy
   □ intellectual disability/mental handicap
   □ brain injury
   □ autism
   □ spina bifida
   □ Other (please describe) ______________________________________

8) How much education have you received?
   □ I did not graduate from high school, but completed school up to grade ______
   □ I finished high school but did not receive a Dogwood Certificate
   □ I graduated from High School with a Dogwood Certificate
   □ I received a GED Secondary School Equivalency Certificate
   □ I received a College certificate
   □ I received a University degree
   □ None of the above
   □ Other (please describe) ______________________________________

9) I was ______ years old when I left or graduated from school.

10) Where did you receive your education in school?
    □ Mostly in resource rooms or special classes
    □ Partly in regular classes, partly in resource rooms or special classes
    □ Mostly in regular classes
    □ Other (please describe) ______________________________________

11) Do you feel that school prepared you for adult life?
    □ Yes □ No □ I'm not sure
12) Where do you currently live?
   □ Institution, hospital, or nursing home
   □ Group home
   □ My family home or apartment
   □ My own home or apartment
   □ Other (please describe)______________________________

13) What kind of recreational and leisure activities do you participate in regularly?
   □ I socialize with friends or family
   □ I do sports (not Special Olympics)
   □ I do Special Olympics
   □ I do outdoor activities (hiking, biking, camping, etc.)
   □ I play games (e.g., board games, video games)
   □ I do hobbies (e.g., arts and crafts, collecting, etc.)
   □ I read
   □ I surf the internet or e-mail other people
   □ I watch TV or movies
   □ I go to public places (e.g., coffee shops, the library, the mall, etc.)
   □ OTHER (please describe)______________________________
   □ None of the above

14) What employment or daytime activities are you currently involved in?
   □ I attend an adult day program
   □ I work in a sheltered workshop
   □ I do volunteer work
   □ I am looking for a job
   □ I have a part-time job (less than 20 hours per week)
   □ I have a full-time job (20 hours or more per week)
   □ OTHER (please describe)______________________________
   □ None of the above

15) What educational activities are you currently involved in?
   □ I am working toward a GED Secondary School Equivalency Certificate
   □ I am taking vocational courses
   □ I am going to College part-time
   □ I am going to College full-time
   □ I am going to University part-time
   □ I am going to University courses full-time
   □ OTHER (please describe)______________________________
   □ None of the above

16) How much support from other people do you need when you are at home or involved in recreation, work, or educational activities?
   □ I need support for all activities
   □ I need support most activities
   □ I need support for some activities
   □ I do not need any support
   □ OTHER (please describe)______________________________
17) What was the name of the communication technology (e.g., electronic communication device, computer with communication software) that you received from SET-BC when you were in school?

18) When you were in school, how satisfied were you with the communication technology that you received from SET-BC? Please rate your satisfaction by circling:

<table>
<thead>
<tr>
<th>RATING SCALE: Circle one only</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>Not at all satisfied</td>
</tr>
<tr>
<td>Don't Know: DK</td>
</tr>
</tbody>
</table>

19) Do you still use the communication technology that you received from SET-BC?

☐ Yes  ☐ No

20) If you answered ‘yes’ to question 19, how satisfied are you now with your SET-BC communication technology? Please rate your satisfaction by circling:

<table>
<thead>
<tr>
<th>RATING SCALE: Circle only one</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>Not at all satisfied</td>
</tr>
<tr>
<td>Don't Know: DK</td>
</tr>
</tbody>
</table>

21) If you are not currently using the communication technology that you received from SET-BC, why are you not using it?

☐ I did not take it with me when I left school
☐ No one helps me to use it
☐ It does not work
☐ It does not meet my current communication needs
☐ OTHER (please describe)
22) How do you currently communicate? (Check all that apply):

- Electronic communication device
  - Name of your communication device: ____________________________
  - Where did you get your communication device?: ____________________________
- Computer with communication software
  - Name of the communication software: ____________________________
  - Where did you get your communication software?: ____________________________
- Communication board, book, or wallet with pictures or symbols
  - Where did you get your communication board, book or, wallet?: ____________________________
- Writing
- Telephone
- E-mail or internet
- Sign Language or finger spelling
- Speech
- Vocalizations
- Gesturing/Pointing
- Eye gaze
- Other (please describe) ____________________________

23) How satisfied are you with your current ability to communicate? Please rate your satisfaction by circling:

<table>
<thead>
<tr>
<th>RATING SCALE: Circle only one</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>Not at all satisfied</td>
</tr>
<tr>
<td>Don't Know: DK</td>
</tr>
</tbody>
</table>
Section 2. Your Communication

In this part you are first asked to rate how important certain areas of communication are to you. Then, you are asked to rate how satisfied you are with your ability to communicate in these areas.

INSTRUCTIONS:

► Rate the importance of the communication items listed on the next page from 1 to 5, using the rating scale at the bottom of the page.

► When thinking of your answer to the importance questions, ask yourself:

   How important is this kind of communication to me in my life?

   OR

   How much do I care about this kind of communication?

► Answer each question in terms of your life as it is right now.
Rate each the following using the scale at the bottom of the page.

**How important to me is communicating...**

1. When I am doing recreation or leisure activities
2. When I am at work (or volunteering)
3. When I am at my day program
4. When I am involved in educational activities
5. With my family or friends
6. With my spouse, partner, or special person
7. With workers in stores, restaurants, movies, etc.
8. With acquaintances and neighbors
9. With people who live far away
10. With personal assistants and/or support workers
11. With doctors, nurses, therapists, dentists, etc.
12. With social workers, vocational service workers, etc.
13. About where I want to live
14. About my privacy and safety
15. About the food I want to eat
16. About my personal hygiene and personal appearance
17. About my physical health
18. About my feelings and mood
19. To make my own decisions
20. To ask for help
21. To tell others where I want to go or what I want to do
22. To tell others that I want or need something
23. To ask questions
24. To be funny (tell jokes)
25. To share love with other people
26. To share my opinions and beliefs
27. To talk on the phone

<table>
<thead>
<tr>
<th>RATING SCALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>Not at all important</td>
</tr>
</tbody>
</table>

Don't Know: DK | Not Applicable: NA
INSTRUCTIONS:

▶ Rate how satisfied you are with the communication items listed on the next page, using the rating scale at the bottom of the page.

▶ When thinking of your answers to the satisfaction questions, ask yourself:

How satisfied am I with my ability to communicate in these areas?

OR

How happy am I with my ability to communicate in these areas?

▶ Answer each question in terms of your life right as it is right now.
Rate each the following using the scale at the bottom of the page.

**How satisfied am I with my ability to communicate...**

1. When I am doing recreation or leisure activities
2. When I am at work (or volunteering)
3. When I am at my day program
4. When I am involved in educational activities
5. With my family or friends
6. With my spouse, partner, or special person
7. With workers in stores, restaurants, movies, etc.
8. With acquaintances and neighbors
9. With people who live far away
10. With personal assistants and/or support workers
11. With doctors, nurses, therapists, dentists, etc.
12. With social workers, vocational service workers, etc.
13. About where I want to live
14. About my privacy and safety
15. About the food I want to eat
16. About my personal hygiene and personal appearance
17. About my physical health
18. About my feelings and mood
19. To make my own decisions
20. To ask for help
21. To tell others where I want to go or what I want to do
22. To tell others that I want or need something
23. To ask questions
24. To be funny (tell jokes)
25. To share love with other people
26. To share my opinions and beliefs
27. To talk on the phone

---

**RATING SCALE**

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all satisfied</td>
<td>Not very satisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
<td>Extremely satisfied</td>
</tr>
</tbody>
</table>

Don't Know: DK  Not Applicable to me: NA
**Survey Help**

1) Did someone help you to answer the questions in this communication survey?

☐ Yes  ☐ No

2) If you answered 'yes' to question 1, who helped you?

☐ Spouse, partner or special person  
☐ Parent or other relative  
☐ Personal Assistant/Paid support worker  
☐ Friend/Advocate  
☐ Other (please describe) _______________________________________________________________________

3) How would you describe the help you received? (Check all that apply)

☐ My helper answered all of the questions for me by thinking about what I would say if I could answer them myself  
☐ My helper answered some of the questions for me by thinking about what I would say if I could answer them myself  
☐ My helper and I talked about all of the questions before I gave my final answer  
☐ My helper and I talked about some of the questions before I gave my final answer  
☐ I answered the questions by myself, but my helper wrote them down  
☐ OTHER (please describe) _______________________________________________________________________

Appendix F

Interview Script

1. What areas of your life are going well right now? (examples: work, social life, school, etc.)
2. What do you think are some of the reasons that things are going well for you in those areas?
3. What areas in your life would you like to see change?
4. What do you think could be done to make changes in those areas?
5. What was positive about your time in school?
6. What do you think are some of the reasons for those positive experiences?
7. What did you not like about your time in school?
8. What could have been done to help things go better in those problem areas?
Appendix G

Notational Conventions for AAC

1. Naturally spoken elements are *italicized*.

2. “Words and sentences produced with digitized or synthesized speech” are italicized and placed in quotation marks.

3. MANUAL SIGNS are in capital letters.

4. GRAPHIC SIGNS and PICTURES are in capital letters and italicized.

5. Some manual signs or graphic symbols need more than one word in translation.

When the gloss of a sign or symbol contains two or more words, these are hyphenated, for example, YOU-AND-ME or SIT-DOWN.

6. S-p-e-l-l-i-n-g is underlined and has hyphens between letters.

7. ‘Interpretations or translations of meaning’ is used for interpretation of manual sign or graphic symbol utterances. It is also used when giving the meaning of facial expressions, gestures, pointing, etc., for example, ‘yes’ (nodding) or ‘no’ (shaking the head).

8. { ... } indicates simultaneous expressive forms, for example speech and manual signs, or manual and graphic signs. For example, {GLAD *I am glad*} means that the manual sign GLAD is produced simultaneously with the spoken sentence *I am glad*.

9. “Printed or hand written words” are in double quotation marks.

Appendix H

Interview Transcription Protocol

1. Review the Generic Interview Protocol.

2. When watching the tape, listen for each question. Watch the tape until you hear the next question or another distinct question: decide which parts of the response to the question were relevant and which parts were irrelevant, tangential.

3. Go back to the tape and transcribe the relevant parts—you do not have to transcribe everything verbatim, as long as the key phrases and points are captured.

4. Make note of the individual's non-verbal behaviours, e.g., gestures, head shakes, obvious facial expressions, getting up from seat, coming back to seat, etc.

5. I may have not asked each question on the protocol—this is because the question was sufficiently answered in the context of a previous question. So, the content between answers may be relevant to the question explicitly answered as well as to other questions on the protocol. Also, respondents may return to the question topics at other points in the interview, especially when they are asked “is there anything else that you would like to say?” etc.