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**APPLICATIONS OF A LIFESTYLE PLANNING PROCESS
FOR PERSONS WITH SEVERE DISABILITIES**

by

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ABSTRACT

This study investigated the efficacy of a "lifestyle" planning process for persons with severe disabilities. The planning process involved five steps: (a) description of a desired integrated lifestyle (pre- test), (b) identification of attitudinal, knowledge, and opportunity barriers present in an individual's service delivery system, (c) development of weekly schedules and plans that are based on an individual's personal preferences (mid- test), (d) implementation of valid teaching technologies and assessments if needed to achieve greater community participation, and (e) application of evaluative measures to monitor success (post- test). The planning process was implemented by means of a consultant model. The process involved planning meetings, on-site visits, in-service training, problem solving, written program planning, and demonstration of instructional techniques. Planning and implementation spanned approximately 12-14 months. The consulting teams were composed of education and behaviour consultants.

Four persons with severe disabilities and challenging behaviour served as subjects. These individuals resided in four communities in the Province of British Columbia, and received consultative services from 1989-1991. Data were collected on three dependent measures at the beginning, midpoint, and end of intervention periods. The measures were type and frequency of integrated activities performed, program quality, and mastery of core steps of priority instructional goals in areas such as behaviour management and augmentative communication.

All four persons engaged in a greater number of preferred integrated activities at the mid- and post- test than at the pre- test. The social networks of all four individuals were higher at the mid- and post- test than at the pre- test. Program quality scores were collected at

the pre- and post- test only. All scores were higher at the post- test than at the pre- test.

Behavioral problems reported at the referral stage were substantially reduced at the post-test for all individuals.

These results are discussed in relation to previous research done in this area.

Limitations of the study are identified, such as sample size, sample bias, and programmatic change that occurred outside of the planning process. Problems in implementing the process by means of a consultant model are discussed and areas for future research are suggested.

Advisor _____

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CHAPTER I

THE SCOPE OF THE STUDY

Background of the Problem

Persons with mental disabilities were feared in ancient times and were often condemned to an atrocious existence, forced to live in total darkness, chained, with little or no ability to move. Although attitudes have changed, community acceptance of persons with mental disabilities is just emerging (Feurstein, Rand, & Rynders, 1988).

The decades spanning 1970-1990 in North America witnessed several significant events that had a direct impact on the degree and kind of integration experienced by persons with mental disabilities. These events can be represented as follows: (a) the introduction of a value based social theory concerning persons with disabilities, (b) the introduction of a public law ensuring that all children regardless of disability shall be provided an appropriate education, and (c) the emergence of public school policy to include all persons regardless of disability in their neighbourhood schools.

The principle of normalization proposed by Wolfensberger (1972) had explicit implications concerning where persons with mental disabilities should live, learn, work, and play. The principle of normalization is defined as: "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible", (p. 28). This principle, combined with the efforts of others such as Blatt (1969), Dunn (1968), Dybwad (1964), and Lilly (1970), led to widespread objection to segregated placements such as institutions, special schools, and special classes (Stainback, Stainback & Bunch, 1989).

Due to the collective efforts of parents, courts and legislatures, P.L.94-142 (Education for all Handicapped Children Act) was passed in the U.S in 1975. This law ensures that no child, regardless of disability, shall be denied an appropriate public education. The late 1970's and early 1980's witnessed the integration of students with severe and profound disabilities into neighbourhood schools. Many of these students had not received any educational services in the past (Stainback et al., 1989). By the late 1980's a number of school boards in Canada and the United states had made it board policy that students with severe and profound disabilities will be fully included in their neighbourhood schools with their brothers, sisters, and friends (Forest, 1987). Concurrently, services to adults with mental disabilities were also evaluated. Sheltered workshops and other "handicapped only" work environments were challenged, and their replacement with "real work", in "real work" environments, was advanced (Brown et al., 1983; Bellamy, Rhodes, Bourbeau, & Mank, 1986).

The focus has now shifted to ways and means of including persons with mental disabilities into the heterogenous activities of a culturally diverse society. This thesis will describe a comprehensive approach referred to as "lifestyle planning" for persons with severe disabilities. Lifestyle planning is a systematic process that focuses on the creation of lifestyles which reflect a balance of integrated recreational, vocational, domestic, and community activities. Within the process, formal and informal services provided to persons with mental disabilities are coordinated to achieve "quality of life" (Wilcox & Bellamy, 1987). Persons with severe disabilities are defined as the lowest intellectually functioning 1% of the population (Brown, Ford, Nisbet, Sweet, Donnellan & Gruenewald, 1982). Persons with dual sensory impairments are included in the definition of severe impairments (Seigel-Causey & Guess, 1989).

Statement of the Problem

A review of the past two decades indicates that there are discrepancies in values, processes, and outcomes as they relate to persons with mental disabilities. Wolfensberger (1980) asserted that human service systems often mirror unconscious patterns of devaluation, and create images and symbols which reinforce cultural stereotypes and dehumanizing roles for people with mental disabilities.

Mount (1987) noted that the process of providing services to people with mental disabilities is becoming increasingly "medicalized", "professionalized", and deficiency-based. Sailor and Haring (1988) estimated that from 60-70% of students with severe disabilities throughout the United States are served in segregated settings. Vocational and residential placements for adults with mental disabilities are similarly restrictive (Bellamy et al., 1986; Hitzing, 1987; Taylor, 1988).

There are few inclusive, comprehensive, and integrated service delivery systems'; the reality for persons with severe disabilities is separation and isolation from mainstream society. If the desired outcome of services is full inclusion in all aspects of community living then new ways and processes need to be developed (Mount, 1987; O'Brien, 1987; Taylor, 1988).

The present study investigated the effectiveness of a planning process which had the purpose of improving the degree and quality of inclusion in integrated activities for individuals with severe disabilities. The purpose of the study was to evaluate the effectiveness of a planning process called the "Lifestyle Development Process" (LDP). This process is divided into five steps and takes the individual and his or her family members, friends, and service providers through a planning and implementation system. The Lifestyle Development Process addresses the following issues: (a) development of an integrated daily schedule

including home, school, vocational, and community activities, (b) strategies to remediate attitudinal, knowledge, and opportunity barriers that foster segregation in the target individual's general community by the service delivery system, and/or school system, (c) creation of meaningful routines based on an individual's capacities, strengths, and preferences, (d) utilization of validated teaching practices to increase independence and participation, and (e) implementation of a monitoring system to ensure teaching/training consistency. Chapter II provides a review of the research literature out of which the Lifestyle Development Process was developed.

CHAPTER II

REVIEW OF THE LITERATURE

This review examines the evolution of planning models for persons with mental disabilities. The most recognized planning models for persons with mental disabilities are: (a) the Individual Education Plan (IEP) (school system), and (b) the Individual Program Plan (IPP) (adult service system) (Mount, 1987).

The Individual Education Plan (IEP)

The IEP is a written plan which includes:

- A statement of the child's present levels of educational performance;
- A statement of annual goals, including short term instructional objectives;
- A statement of the specific special educational and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs;
- The projected dates for initiation of services and the anticipated duration of the services; and
- Appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved. (P.L. 94-142, Rules and Regulations, Section 121a.346, p. 42491)

Kaye and Aserlind (1979) reviewed the implementation of Individualized Education Plans (IEPs). Their study, called Project IEP, was based on information gathered from the States of Alabama, New Jersey, Washington, and Wisconsin. Trained interviewers conducted several hundred interviews with parents, teachers, support, and administrative personnel.

The IEP process was conceptualized as occurring in the following phases: (a) development of the written IEP, (b) implementation of the goals and instructional objectives, (c) evaluation of the efficacy and achievement level described in the written product, and (d) modification and/or retention of the written IEP. This study concluded that all parts of the process must be dealt with in a comprehensive and detailed manner or the IEP will suffer. If the resulting IEP is not stated in clear, unequivocal terms, and if it does not reflect the vital aspects of a rich educational experience, the child will ultimately suffer (Kaye & Aserlind, 1979).

Brown et al. (1980) noted that the general guidelines regarding IEPs as mandated in the U.S. P.L. 94-142 did not ensure that functional, chronological age-appropriate curricula would be developed. These authors described the process components of generating comprehensive, longitudinal, and chronological-age-appropriate IEPs. These are: (a) well defined strategies for organizing curricular content, (b) involvement of parents in decisions concerning their son/daughter, and (c) a framework for developing, implementing, and evaluating empirically valid instructional programs.

Billingsley (1984) reviewed the content of 22 IEP's in two school districts. There were 499 IEP objectives cited; of these, two-thirds targeted functional behaviours, such as skills that were required in the students' home and community environments (Snell, 1983). Fewer than (10%) of these objectives contained a generalized outcome. Billingsley noted that a potentially functional skill is virtually useless if it can only be performed in an artificial training setting and is not being taught or performed in targeted natural environments (Brown, Nietupski, & Hamre-Nietupski, 1976). Billingsley also found that the long range goals were consistently so broad and general in nature that the researchers could not interpret what the

specific outcome was intended to be. The subjects of this study were served in segregated facilities.

Hunt, Goetz, and Anderson, (1986) compared the IEP's of 18 students from segregated schools and 18 students from integrated schools. These authors found a significant relationship between program placement and the quality of IEP objectives for students with severe disabilities. Students in integrated schools had significantly higher scores on measures of age appropriateness of materials, functionality of basic skills, and potential for generalization of skills to a variety of environments. It cannot be assumed that there is a direct relationship between IEP objectives and the actual implementation of those objectives. The necessary and desired outcome of the IEP process should be actual implementation of the goals and objectives in real world integrated environments (Brown et al., 1983). Hunt et al. (1986) identified the need to further investigate the correlation between the IEP and day-to-day educational programming.

Lynch and Beare (1990) investigated the relationships between stated IEP objectives and actual classroom instruction. They reviewed the IEPs of 48 elementary and secondary students with mild behavioral and/or intellectual handicaps and found the IEPs to be adequate in the categories of age-appropriateness, functionality, and generalization. However, no significant relationships were found between the content of the IEP and the actual activities of the instructional day. Many of the students' activities were inappropriate for the age of the students. The activities focused on an instructional model designed for much younger students.

Inconsistency between the stated IEP and the outcome may be partially explained by the findings of Dudley and Curtis (1985) who reported that teachers do not usually use the

IEP for planning day to day instruction. Gerber, Banbury, Miller and Griffin (1986) surveyed 144 special educators, (44%) of respondents perceived the IEP conference as a formality. Gerber et al. (1986) also reported that (70%) of the respondents felt that parents should waive their right to attend meetings. These authors concluded that the IEP conference did not function well as a vehicle for shared decision making between parents and professionals.

Several studies reported on the attitudes of parents and professionals as they relate to role definitions, interpersonal relationships and assumptions of competence (e.g., Cutler, 1981; Darling & Darling, 1982; Donnellan & Mirenda, 1984; Seligman, 1979). A number of prevalent and disturbing issues were identified which tended to jeopardize meaningful planning. Professionals received minimal training in developing the communication and practical skills necessary to work with a team that includes parents (Darling, 1983; Seligman, 1979). Authority has traditionally been invested in the professionals, and parents have been relegated to passive and grateful recipients of services (Darling, 1983; Lyon & Preis, 1983).

Gerber et al. (1986) found that including parents in the IEP process does not ensure parent participation in making important decisions. Gilliam and Coleman (1981) reported that the IEP process is dominated by professionals. If the parents are present they are afforded minor roles in terms of contribution and influence. Turnbull and Turnbull (1986) suggested the need for professional and parent collaboration to promote effective IEP planning. Biklen (1982) and Taylor (1988) noted that the IEP process does not liberate students from the biases and beliefs about handicaps or provide new directions for change in both planning and implementation.

The Individual Program Plan (IPP)

Adults with mental disabilities are typically served in residential and day programs. These programs are based on the assumption that a range of services are needed for persons with mental disabilities (Taylor, 1988). There is a generally accepted rank ordering of these services based on the restrictiveness of the program (Turnbull, Ellis, Boggs, & Biklen, 1981). Persons with developmental disabilities are placed within this continuum based on their degree of disability and are assumed to transition to a less restrictive placement when a set of requisite skills have been mastered. The most restrictive residential and day programs are the most segregated (Hitzing, 1987). Residential programs include state supported institutions, private institutions, group homes, and semi-independent living arrangements. The day/vocational programs include day training or day treatment programs, sheltered workshops, and competitive employment (Schalock, 1983). This continuum of day/vocational and residential options represents the principle of the least restrictive environment (LRE) (Taylor, 1988).

The planning process for adults with mental disabilities is the Individual Program Plan (IPP). Despite the fact that IPPs are widely used, the assumptions and efficacy of this process has not been examined (Mount, 1987). The IPP process as described by Mount (1987) and Gardner (1980) is similar to the IEP with regard to process, content, and outcome measures. Within the adult service system, two important issues challenge the planning process: (a) the pervasiveness of the LRE principle, and (b) the identification of a rich and valued lifestyle for the person involved in the process. Mount (1987) reviewed the guidelines for the IPP in accredited adult service agencies throughout the United States. She noted four major components of the IPP process: (a) assessment, (b) planning, (c) delivery of services, and (e) evaluation of services by an interdisciplinary team.

Mount (1987) identified a number of areas in the IPP planning process which did not lead to fulfilled or meaningful lifestyles for persons with mental disabilities. Hammill and Bartel (1975) and Salvia and Ysseldyke (1985) found the IPP to focus on the deficits of an individual and planning was centred on the amelioration of these deficits. These deficits were identified by assessments which employed standardized tests (Gardner, 1980). When a team of professionals were involved team members tended to develop separate plans and provide isolated services (Gardner, 1980). Hermery (1987) reported that there was confusion and lack of communication among and between family members, staff, and professionals working on IPP teams regarding individual roles and responsibility.

Mount (1987) described the contemporary human service system as "closed", replacing community roles and relationships with goals and outcomes which have little to do with participation in the general community. This is particularly true of persons with severe disabilities who are supported and maintained in the most restrictive ends of the residential and day programs (Braddock, Hemp, & Fujiura, 1986; Bellamy et al., 1986).

Lifestyle planning or futures planning, in contrast, is a more comprehensive approach. The planning process is designed to develop an integrated life as the desired outcome. Planning models insure that family members, friends, and neighbours assume integral roles in decision making (Vandercook, York & Forest, 1989). Quality of life as described in the lifestyle planning process has been based on the work of E. A. Singer, cited by Ackoff and Emery (1972), Churchman (1982), Emery and Emery (1976), and Gharajedaghi (1984). Five lifestyle outcomes define a quality of life and constitute a definition of the principal of normalization, (O'Brien, 1987). O'Brien (1987) asserted that the lifestyle planning process offers better quality of life experiences for persons with disabilities, than traditional planning models.

"Life-style Planning" (O'Brien & Lyle, 1987; O'Brien, 1987), "Personal Futures Planning" (PFP), (Mount, 1987; Mount & Zwernik, 1988), and the "McGill Action Planning System" (MAPS) (Forest & Lusthaus, 1987), are examples of lifestyle or futures planning reported in the literature.

Life-style Planning

O'Brien (1987) described a planning process called Life-style planning which systematically guides family members, friends, and service providers through three planning activities: (a) statement of a desirable future for the individual, (b) delineation of the activities and supports necessary to ensure that goal, and (c) acceptance of responsibility for use of available opportunities or development of needed activities and community supports such as securing job opportunities in the general community and the utilization of friends and neighbours as teachers.

This type of planning makes explicit the role of formal and informal resource systems and is based on the notion that cooperative efforts by family members, friends, and service providers are necessary if a quality lifestyle is to be achieved for the individual with a disability (O'Brien, 1987). Community presence, choice, competence, respect, and community participation are quality of life criteria (O'Brien, 1987; Mount & Zwernick, 1988). Planning for quality of life outcomes involves a series of meetings. The first planning meeting comprises those key people who most influence the individual's quality of life. The individual's current lifestyle is reviewed prior to the planning meeting in order to identify the person's present relationships to family, community, people, places, and activities.

The issues addressed at the planning meeting include: (a) quality of the persons present life experiences, (b) changes needed to improve experiences, (c) concerns and opportunities for improvement of lifestyle and, (d) removal of critical barriers to lifestyle improvement. The outcomes of the planning are written in summary form and submitted to

each participant. Two weeks after the life-style planning meeting, the people directly responsible for managing the individuals schedule meet to review the activities in which the person is presently involved. A month later, the individual responsible for convening the first planning meeting reviews the commitments made and communicates with participants in order to identify areas that need improvement (O'Brien, 1987).

Personal Futures Planning

Building on the concept of lifestyle planning, Mount (1987) developed the PFP process. The five essential lifestyle outcomes and accomplishments developed by O'Brien and Lyle (1987) provided a framework for desired outcomes in the PFP process. Mount identified seven steps to the PFP process:

- 1) develop a personal profile of the focal person, emphasizing their strengths and capacities;
- 2) review issues and trends in the surrounding environment that are likely to influence the quality of the focal person's life;
- 3) create and find desirable goals for the future including vocational and residential options within the general community;
- 4) identify obstacles and opportunities within the service delivery system and general community;
- 5) identify implementation strategies for desired directions;
- 6) establish priorities for implementation;
- 7) identify additional issues which may restrict community participation.

Mount (1987) reviewed the effectiveness of this procedure with a group of six persons with mental disabilities who were in transition from high school to adult life. She compared the results of the PFP planning events with the contents of IPP documents of six persons with mental disabilities in a control group. She found that after one year the IPP did not produce

any changes in the lives of the individuals in a control group, compared with the PFP process which was reported to have contributed to two major life changes. Staff in the PFP process maintained rich visions of the future and learned to manage change for the individuals for whom they were responsible (Mount, 1987).

There are two differences between the PFP process and the IPP process. First, the PFP process developed services based on the informed choices, strengths, and needs of individuals, rather than on the needs of the service delivery system. Second, the PFP process enhanced the abilities of ordinary citizens, co-workers and neighbours to provide skill teaching and helped individuals to form relationships and participate more fully in their communities (Mount & Zwernik, 1988).

The McGill Action Planning System (MAPS)

Vandercook et al. (1989) described a futures planning process designed for the education system. The McGill Action Planning System (Forest & Lusthaus, 1987) focuses on the inclusion, participation, and learning of students with disabilities in integrated school settings. The desired outcome of the MAPS process is the full inclusion of students with high needs into regular age-appropriate classes. Relationships are cited as markers of quality of life as well as enhancers of social and cognitive development (Lewis, 1982).

Four assumptions guide the MAPS process: (a) integration, (b) individualization, (c) teamwork and collaboration, and (d) flexibility. MAPS involves a planning meeting and a planning team. The planning team consists of the individual, family members, friends, and both regular and special education personnel. The inclusion of non disabled peers in the planning process is a unique component of MAPS. The MAPS process has been used with over 200 school age children with moderate to profound disabilities in 50 school communities (Vandercook et al., 1989).

The evolution of planning processes for persons with disabilities is increasingly focusing on the mainstream of society (Vandercook et al., 1989). These processes are beginning to incorporate elements of planning models used by the nonhandicapped population, and are increasingly referencing lifestyle quality as described by the general population as the desired goal (O'Brien 1987; Mount 1987; Vandercook et al., 1989).

Life/work Planning

Life/work Planning is typically utilized by job hunters and life planners in the "real" world (Bolles, 1984). The intent of Life/work planning is to empower the individual planners to gain more control of their lives and experience a better quality of life. Bolles assumed that the time spent on learning, working, and playing is out of proportion. He challenged the cultural expectation that life should consist of a rigorous regiment of schooling, a schedule of work, and finally a schedule of leisure or play upon retirement which he called "boxes" (Bolles, 1984).

In contrast, Life/work planning is a systematic and intensive life long endeavour designed to achieve a balance between learning, working, and playing. The critical items of Life/work planning are: (a) skills identification; (b) skills listing; (c) clustering of skills; (d) development of an action plan; (e) development of an ultimate life goal; (f) development of immediate job/life objectives; (g) systematic targeting; (h) meeting individual targets; and (i) implementation of a feedback system to ensure survival (Crystal & Bolles, 1984).

A system of identifying personal learning strengths and styles, "linking up", and evaluating and planning alternatives is essential to the process. The process is specific, systematic, and comprehensive (Bolles, 1984).

Brown et al. (1983) identified several learning characteristics of persons with severe disabilities which necessitate a systematic, specific, and comprehensive approach to teaching: (a) skill acquisition occurs at a slow rate and skills being taught should have direct relevance

to daily functioning, (b) complexity of skills being taught should be carefully balanced to ensure that individually relevant skills are acquired, (c) the transfer and generalization of skills across different environments is not reliable and (d) the synthesis of separate skills cannot be assumed. It is important to discuss some teaching technologies used with persons with mental disabilities, as they are part of lifestyle planning.

Teaching Technologies

Nevin and Thousand (1986) reviewed practices which supported inclusion of students with disabilities in the mainstream of education. Curricular adaptations and general education teachers who can design and implement the adaptations were both shown to increase academic growth for all students including those with disabilities. Mastery learning (Block, 1974), individualized learning (Bloom, 1980; Froh & Muraki, 1980) and cooperative learning (Johnson, Maruyama, Johnson, Nelson, & Skon, 1981; Slavin, 1984) were shown to be particularly effective.

Hall, Lund, and Jackson (1986), Hall and Copeland (1972), and Haring, Lovitt, Eaton, and Hanson (1978) noted applied behavioral analysis increased teachers' abilities to include students with handicaps in mainstreamed classes (Nevin & Thousand, 1986). White (1984) reported that highly structured programs with well defined objectives were superior to programs lacking these components (Nevin & Thousand, 1986). A task analytic approach and ecological inventory strategies have been shown to be effective as well (Browder & Stewart, 1982; Falvey, 1986; Sailor & Guess, 1983; Snell, 1983; Wehman et al., 1985).

In addition non-aversive behavioral support incorporates analyses of (a) ecological/environmental considerations, (b) curricular programmatic considerations, (c) communicative functions, and (d) antecedent and consequence considerations (LaVigna & Donnellan, 1986). These analyses enable appropriate adaptive interventions (Evans & Meyer, 1985; Horner, 1991). Finally, Mirenda Iacono and Williams (1990) described the

"Participation Model" (Rosenburg & Beukelman, 1987) which provides communication assessment and intervention. The model incorporates opportunities for communication and access to opportunities. This model assists individuals with severe communication deficits to improve their communication skills in a range of integrated activities with an increased number of communication partners (Mirenda et al., 1990).

Summary of Review

In its infancy the individual planning process was an open ended process that measured goals and learning objectives but seldom defined or evaluated these goals in terms of lifestyle quality (Mount, 1987; O'Brien, 1987; Brown et al., 1980). In response to these deficiencies a number of lifestyle or futures planning models were developed. These futures planning models focus on full inclusion of individuals with severe disabilities in school and community environments (O'Brien 1987; Mount, 1987; Vandercook et al., 1989).

Although no definitive lifestyle measure exists (O'Brien, 1987; Kennedy, Horner, Newton, & Kanda, 1990) a growing number of researchers have begun to focus on activity patterns as a potential and promising element of quality of life measurement (Kennedy et al., 1990). This recent attention to lifestyle quality for persons with disabilities has resulted in the assumption that an improved social life is one of the most critical and life enhancing outcomes of effective community support for this population (Kennedy, Horner, & Newton, 1990). As well, research attention has focused on identifying and measuring quality programming for persons with severe disabilities (Meyer, Eichinger, & Park-Lee, 1987). The study presented in the next chapter analyzed the application of these planning, intervention, and measurement procedures, to planning for individuals with severe disabilities.

CHAPTER III

THE PRESENT STUDY

The purpose of this investigation was to demonstrate the efficacy of the Lifestyle Development Process (LDP) for planning quality lifestyles for persons with severe handicaps. The LDP was designed to provide a comprehensive lifestyle approach that also addressed teaching and program issues for this population.

The LDP was implemented using the consultant model described by Janney and Meyers (1990). The LDP was tested under field conditions with individuals with severe disabilities in various communities throughout the Province of British Columbia. The three areas of lifestyle quality that were measured were activity patterns, program quality, and skill acquisition. The activity pattern measure was a measurement developed by Wilcox and Bellamy (1987) for use in community-based residential programs supporting people with severe disabilities. The quality of the program offered to the subjects in this investigation was evaluated with a measurement developed by Meyer et al. (1987) which evaluates the content of educational services for students with severe disabilities. The LDP focused on three areas of technical assistance: (a) non-aversive behaviour management (LaVigna & Donnellan, 1986), (b) communication assessment and intervention (Mirenda et al., 1990), and (c) task analyzed instructional techniques (Falvey, 1986; Brown et al., 1980). Evaluation of skill acquisition in these areas involved a review of daily logs, recorded data, direct observation, interviews, and videotape analysis. The dependent variables of the present study were measured three times over a 6-18 month period.

Four single case studies were examined in this investigation. The triangulation and multimethod procedure described by Borg and Gall (1989) was utilized. This procedure refers to the usage of a number of data collection instruments, such as tests, direct observation, interview, and content analysis.

Hypotheses

The study addressed the following three hypotheses:

1. The degree and kind of integrated activities engaged in by children and adults with mental disabilities will be positively affected by the five steps of the Lifestyle Development Process.

Activity Patterns

The monthly activity patterns of subjects will reflect a greater number of preferred integrated activities being performed at the mid- test (completion of step 3 of the LDP) and post- test (completion of step 5 of the LDP) than at the pre- test (Step 1 LDP).

Social Network

The social networks of subjects will reflect a greater number of activities being engaged in with persons outside of their paid service system at the mid- test (completion of step 3 of the LDP) and post- test (completion of step 5 of the LDP) than at the pre- test (step 1 LDP)

2. The Program being offered to children and adults with mental disabilities will reflect a greater number of most promising practices in the area of education of students with severe disabilities after the implementation of the five steps of the LDP (post- test) than at the referral stage (pre- test).

Program Components

Six content areas will be reviewed prior to the implementation of the five steps of the LDP (pre- test).

- 1) program philosophy;
- 2) program design and student opportunities for learning;
- 3) systematic instruction and performance evaluation;
- 4) IEP/IPP development and parent participation;

- 5) staff development and team collaboration; and
- 6) facilities and resources.

These content areas will be reviewed after the implementation of step 5 of the LDP (post- test).

3. Subjects will have mastered the core elements of their technical assistance strand (step 4 LDP) at the program post- test (step 5 LDP).

Method

Subjects

The investigation involved two children and two adults with severe handicaps. The subjects were selected on the basis of the following criteria.

- a) diagnosis of a mental handicap;
- b) referral for consultative services was initiated by the school, government agency, service provider, or family member; and
- d) individuals and their service providers exhibited the willingness and ability to complete the five steps of the LDP.

Table 1 provides selected demographic information regarding the four subjects. There were three females and one male ranging in age from 8-54 years. One subject had a diagnosis of sanfilipo syndrome (MPS III), one subject had autism, one subject was diagnosed as deaf blind rubella syndrome, and one subject was described as severely mentally handicapped. The subjects were referred to the consulting teams for educational and lifestyle planning.

Settings

The subjects resided in four different regions of British Columbia. Consultative services were provided to individuals, family members, and service providers in their home districts.

Table 1

Selected Demographic Information for Subjects

<u>Subject code</u>	<u>Sex</u>	<u>Birth date</u>	<u>Medical diagnosis</u>	<u>Residence</u>	<u>Educational/Voc. placement</u>
Subject 1	F	9/26/57	Rubella syndrome	Natural home	Home based program
Subject 2	M	6/10/37	Severe mental retardation	Duplex adult services	Community based day program
Subject 3	F	11/25/83	Autism	Natural home	Home school integrated class primary
Subject 4	F	6/15/83	Sanfilippo syndrome	Natural home	Segregated class elementary

The school age subjects were enrolled in the public school system. The adult subjects were served by the adult service branch of the Provincial Ministry of Social Services and Housing. One adult subject resided in a duplex with one other individual with a mental handicap. The residence was in a culturally diverse working class area of an urban centre. The other adult subject resided with her parents in a small sea side community. This subject participated in a day program only. The model utilized was primarily home based, though some community programming was evident.

Description of Consulting Teams

Two separate consulting teams provided services to the children and adult subjects. The LDP was implemented by both teams. The adult team consisted of a speech and language pathologist, three behaviour consultants, and one instructional consultant. The childrens' team consisted of two education/behaviour consultants.

There were 4 parts to the consulting process:

1. A referral was made to the consulting agency for consultative services. These referrals were initiated by a number of individuals including social workers, parents, service providers, and school personnel.
2. An initial planning meeting was convened with all relevant parties (family members, friends, social worker, service provider etc.). The consultant explained the Lifestyle Development Process. The role of the consultant was to assist in the development of the action plan and the development of the technical strategies but was not intended to supplant the traditional roles of the service delivery or educational staff (Janney & Meyer, 1990).
3. The consultant conducted an assessment of existing and previous placements. Existing and previous treatment plans were also reviewed. Assessment included: (a) background history, (b) day and week plans, (c) program placement, (d) intervention strategies, and (e) mediator analyses. A meeting was held to discuss projected timelines and responsibilities.

4. The implementation of the planning process involved a variety of on-site visits, in-service training, problem solving, written program planning and demonstration of instructional techniques (Janney & Meyer, 1990). The time of implementation varied, ranging from 6 months to 24 months. The consultant usually met team members on a varying schedule beginning with once a week, decreasing to once a month, etc.

Step 1 Vision Planning

This step of the Lifestyle Development Process assisted family members, peers, and service providers to begin planning a vision of a quality life in the community for the individual. It included a process for examining the existing daily and weekly schedule of the individual and comparing that to the schedule of a non-disabled person of similar age. The differences in lifestyles were identified and documented as baseline information. Step 1 involved the application of pre- test measures.

Step 2 Assessing Barriers to Participation

This step involved a process for assessing and identifying the attitudinal, knowledge, and opportunity barriers that may have existed in the service delivery system and/or community. Inservice materials (e.g., videotapes, consumer presentations, etc.) were used to assist service providers to remove or remediate the obstacles that were interfering with the individual's ability to achieve participation in the community. If opportunity barriers persisted in the service delivery system, meetings were held with the key people who possessed the authority to ensure community participation. Specific barriers were identified prior to the meeting. Recognized experts in the area of community integration of persons with disabilities were consulted, and provided input at these meetings.

Step 3 Assembling Meaningful Routines and Schedules

This step concentrated on identifying the capacities, strengths, and preferences of the individual. Service providers were taught to identify where and with whom the individual may

want to live, work, relax and spend leisure time (adult service model). If the individual was in the school system, service providers were taught to analyze the daily school schedule and curricular content and ensure that it reflected the individuals learning strengths, styles and capacities. This process involved the individual directly and also relied on the key people who knew the individual best. This involved planning meetings, informal home and community based interviews, and observations. The result of this step was the development of an action plan, including goals and objectives related to where the person will live, work, go to school, and have recreation. Appendix A contains a number of sample inventories which represent a section of the product component of the LDP. The mid- test measures were applied after the implementation of step 3.

Step 4 Development of Intervention Strategies

In Step 4, service providers applied whatever assessment and implementation strategies were necessary to achieve the stated goals. This phase offered training in: (a) non-aversive behaviour management strategies and assessment, (b) augmentative and alternative communication assessment and intervention techniques, and (c) individualized adaptations and /or instructional strategies as needed. This step also included necessary assessments (i.e. orientation and mobility, visual/auditory impairments, etc.). See Appendix B for sample assessment tools.

Step 5 Evaluate Effectiveness/Develop Monitoring System

The goals, objectives, and intervention strategies identified in the preceding steps were reviewed to determine if they were reflected in the individuals' day and week plan. This review determined whether or not the discrepancies between the lifestyle of the target individual and his /her non-disabled peers that were identified in step 1 were reduced. Finally, a monitoring tool to ensure staff consistency was implemented. The post- test measures were applied after the successful completion of step 5.

Qualitative data were gathered in informal interviews, written inventories, field observations, and video tape analyses. These measures occurred throughout the planning process. Three validated quantitative measures were also utilized.

Measures

1. The Resident Lifestyle Inventory (RLI)

The (RLI) Wilcox and Bellamy (1987) has been shown to be a valid and reliable instrument. It is an activity measurement tool which is used in community-based residential programs for people with severe disabilities. The RLI measures what types of activities are performed during a one month period, how often each activity occurs, which activities are preferred, the level of support needed for participation, and where the activity typically occurs.

The RLI has a moderate-to-high percent agreement score across four variables: (a) activity type, (b) activity location, (c) activity frequency, and (d) level of support. The RLI was administered at the pre- test (step 1) mid- test (completion of step 3) and post- test (completion of step 5) intervals of each case study. Appendix C is a research protocol for the RLI.

2. Social Network Analysis Form (SNAF)

The Social Network Analysis Form (SNAF) measures the social networks of persons with disabilities and is commonly used in conjunction with the RLI (Kennedy et al., 1990). The SNAF is used in a face to face interview format to gather information concerning those persons who are socially important and the types and frequency of activities performed with these people. Kanda (1989) reported that the SNAF shows overall test-retest reliability. Appendix D includes the research protocol for the SNAF and a sample question sheet.

3. Program Quality Indicators (PQI)

The Program Quality Indicators checklist (PQI) (Meyer et al., 1987) is a 122 item checklist. The items of the Program Quality Indicators are important indicators of best educational practices for students with severe disabilities. The PQI checklist is listed in Appendix E.

CHAPTER IV

RESULTS

Laura (Subject 1)

Laura is a 34 year old woman who lives with her parents in a small sea side community in British Columbia. Laura is visually and hearing impaired due to rubella. Laura has cataracts, extremely limited vision, and profound hearing loss. Laura had never attended an educational setting with nonhandicapped persons. Instruction was either provided in her home or in segregated facilities. Prior to the referral for consultative services Laura had never experienced a "real" job in the community with nonhandicapped persons. Lack of educational services in the past denied her the interventions needed by persons with dual sensory impairments. Laura uses Blissymbols (Hehner, 1980), written words, gestures, and vocalizations for communication.

Laura was referred to the consulting team by her parents and social worker. The main concerns at the time of referral were Laura's lack of effective communication skills and excessive ritualistic or stereotypic behaviours commonly associated with sensory deprivation. The goal was to develop a community based program.

Step 1 Vision Planning

An initial planning meeting was attended by two members of the consulting team, Laura, Laura's parents, Laura's social worker, and a friend of Laura's in September, 1988. Pre- test data were collected at this time. Laura was reported to enjoy and be independent in a range of community activities. The following goals were identified for Laura, (a) seek meaningful employment, (b) develop relationships in the community, (c) develop communication skills, and (d) exercise more. A review of Laura's day and week plan illustrated a considerable discrepancy between this desired outcome and Laura's existing lifestyle. Laura engaged in a total of 39 community activities for the entire month prior to the

start of intervention. She went swimming once in that month and ate at a restaurant once. She went shopping for groceries twice per week and visited the post office three times per week. These two activities accounted for (62%) of Laura's community based activities.

Table 2 is a summary of Laura's preferred activities as listed by her family and friends during the planning meeting. Table 3 is a typical day for Laura prior to intervention. Table 4 compares Laura's activity patterns and social network at the pre- mid- and post- test. At the pre- test there were eleven members reported to be socially important in Laura's life. Of this number, nine persons were either family members or paid human service workers. The pre- test overall PQI score for Laura's program was (32%) with the lowest scores reported in the areas of (a) program philosophy (28%), (b) IPP development and parent participation (25%), and (c) staff development and team collaboration (28%). Table 5 compares overall scores and area and item scores of the PQI for Laura's program at the pre- and post- test.

Step 2 Assessing Barriers to Participation

A review of program plans, interviews with relevant persons, and direct observation of program implementation revealed a number of barriers to Laura's community participation. One barrier was Laura's ritualistic or stereotypic behaviour at bedtime. If Laura had a poor nights' rest, she was typically too tired or disinterested to access the community. Other substantive barriers were also present. The service provider used a service delivery model that was based on the notion that the most appropriate placement for Laura was in a specialized group home for other persons with dual sensory impairments. Laura's parents disagreed with this view.

Table 2

Summary of Laura's (Subject 1) Preferred Activities

Step 1 Vision Planning Meeting

Domestic

- 1) folding laundry
- 2) cooking
- 3) self-care (beauty aids etc.)
- 4) loading the dishwasher
- 5) making the bed

Community

- 1) visiting Sarah for tea
- 2) going to post office
- 3) going to a restaurant
- 4) purchasing groceries
- 5) getting hair done

Potential Jobs

- 1) stocking shelves at the red & white
- 2) folding laundry at the lodge
- 3) delivering mail

Leisure

- 1) swimming
- 2) bike riding
- 3) visiting friends
- 4) gardening
- 5) walking on beach

Table 3
A Typical Day for Laura (Subject 1)
Pre- Test September, 1988

8:00	wake up (perform morning routine)
10:00	prepare and eat breakfast
11:00	go to house of paid human service worker (talk about day plan)
11:15	perform colouring and table work
12:00	make lunch, eat lunch
1:00	table work (match and or write Blissymbols)
2:00	go to post office (pick up mail)
3:00	return home
5:00	eat dinner
7:00	begin bedtime routine (engaged in ritualistic behaviours until she fell asleep)

Table 4

Category Sum Scores of Activity Patterns for Laura Pre- Mid- Post- Test

	<u>RLI</u>	Pre	Mid	Post
Total number of activities performed		101	360	286
Total number of different activities performed		24	31	36
Total number of preferred different activities performed		17	28	35
Total number of preferred community activities performed		39	77	84
<hr/>				
	<u>SNAF</u>	Pre	Mid	Post
Total number of people paid to provide service		4	1	2
Total number of activities performed with paid people		25	60	55
Total number of friends		2	2	3
Total number of activities performed with friends		8	8	10
Total number of neighbours/others		0	1	1
Total number of activities performed with neighbour or others		0	1	4
Total number of family members		5	5	5
Total number of activities performed with family members		53	50	50
Total number of co-workers		0	1	1
Total number of activities performed with co-workers		0	4	4

Table 5

Percentage Area and Item Scores And Overall Percentage PQI Score for Laura's
Program at Pre- Post- Test

	Pre	Post
1.Program Philosophy (items 1-18)	28%	81%
2. Program Design and Student Opportunities for Learning (items 19-27, 33, 34, 36)	38%	73%
3. Systematic Instruction and Performance Evaluation (items 41 through 64)	42%	60%
4. IPP Development and Parent Participation (items 65-84)	25%	80%
5 Staff Development and Team Collaboration (items 85-86, 89-90, 95-96, 101)	21%	71%
6. Facilities and Resources (items 105-123 were not appropriate for adult services)		
Overall PQI Percentage Score		
	Pre	Post
Overall PQI Score	32%	72%

The notion of developing a community based program for Laura in her home community was explained to the parents, social worker, and service provider. Video tapes, records, and discussions with recognized experts in the field provided a basis for this plan. After considerable consultation it was agreed that a work and recreational program for Laura in her own community would be attempted. The adult consulting team agreed to assist the parents in training a new service provider to implement the LDP. It took a number of months before the previous services were phased out and a new plan implemented.

Step 3 Assembling Meaningful Routines and Schedules

One important goal was for Laura to experience a "normalised" routine that encompassed meaningful work. Socializing with peers, earning money, and spending it on preferred items was another goal. The consulting team assessed Laura's strengths and needs in a range of community, recreational, and vocational environments. Laura's revised day and week plan at the mid-intervention test reflected her family's desires for her.

In May, 1989, mid- test measures were administered (see table 4). Laura had engaged in a total of 360 activities at the mid- test. Thirty one different activities were performed during this month; of these, 28 were preferred activities. The total number of preferred community activities performed during this month was 77. One of these was stocking shelves at the grocery store once per week. This was a volunteer placement and was Laura's first integrated job placement.

Step 4 Develop Intervention Strategies

After one month of a varied community based program Laura's strengths and needs began to emerge. She mastered the steps of her routines easily. However, when delays or interruptions occurred she became agitated and reverted to ritualistic behaviours, such as tracing and retracing her steps. She did this for hours at a time.

The consultants assisted the service providers to: (a) conduct a functional analysis of behaviour (LaVigna & Donnellan, 1986), (b) develop task analyses', and ecological inventories (Falvey, 1986) and (c) follow the core elements of the Participation Model of communication assessment (Mirenda et al., 1990). After these analyses were completed, a number of related intervention strategies were developed.

First, it was considered important to reduce and eventually eliminate the ritualistic behaviours that were interfering with Laura's social integration. Laura had several signals that indicated the beginning of her ritualistic behaviours. These signals consisted of her tightening her facial muscles, shaking her head in quick short movements, and twitching her hands in a back and forth motion. This behaviour was treated as a meaningful communication and interpreted as, "help, I don't know what comes next". Laura was taught to identify the symbol and written word for "help" in her communication book. Laura was then provided with informational cues (Blissymbols) illustrating the next sequence in her routine. Without such cues Laura seemed to lose the sequence, and retraced her steps to the beginning of the sequence. Once she was engaged in such a ritual, Laura refused to accept further instruction.

Communication

In spite of her severe visual impairment, Laura relied on her vision to interpret information. She was able to Identify a 1/4 inch by 1/4 inch Blissymbol with 100% accuracy. Laura also recognized photographs. Laura's current system of communication consists of a combination of Blissymbols, gestures, eye gaze, vocalizations, written words, and photographs. A review of Laura's programming history revealed a number of communication assessments and recommendations, but consistent communication programming occurred only sporadically.

A pictorial calender and time management system were also developed, and specific communication strategies were identified within each routine. With the pictorial calendar and

daily schedule of activities, Laura was able to consistently perform her morning routine with no interfering ritualistic behaviours, and to experience a full day in the community. Without her pictorial guide, Laura reverted to her ritualistic behaviours and often missed work or other portions of her day in the community. Finally, Laura's communication partners were taught to pair written words with Blissymbols and systematically fade the Blissymbols. Laura's capabilities with other aided communication devices such as a computer and symbol book were also assessed.

Laura's service providers and parents were taught to conduct task analyses for new routines. Laura learned new routines within one or two trials. Once a skill was mastered the original teaching sequence was rigidly adhered to. If Laura was taught a new skill sequence in an inconsistent or erratic manner, she found it difficult to learn, and responded by a ritual and refused further instruction. Laura's routines were videotaped to demonstrate the correct sequence and she enjoyed watching herself on television. The videotapes were used as a teaching tool for Laura and a training manual was developed for Laura's mother. The training manual consisted of Laura's preferred activities, the core instructional components of the activities, and communication strategies within each activity. Areas for future enrichment were also listed. Laura's mother expressed the desire to train Laura's service providers and she recruited other people to facilitate Laura's community integration.

Step 5 Evaluate Effectiveness/Develop Monitoring system

At the one year follow up test in June, 1990, Laura engaged in a total of 267 activities (see table 4). Thirty six different activities were performed; of these, 35 were preferred activities. A total of 84 preferred community activities were performed during this month. These preferred activities included weekly participation in the following: (a) folding laundry at a lodge, (b) buying a meal at a restaurant, (c) swimming at the community pool, and (c) baking at a friends house. Laura's social network consisted of 12 people. Three

outside of her paid and family circles had joined her network. Laura visited with a new friend in the community twice per month, and received feedback and encouragement from a restaurant proprietor whom she visited once per week. Laura was also interacting and receiving instruction from her supervisor at work (see table 4 SNAF). The overall PQI score at post implementation was (72%). All area and item scores of the PQI were higher at the post implementation test than at baseline (see table 5).

Laura's communication skills steadily improved. Her written vocabulary was increased by twenty Blissymbols, she had learned to write the names of people in her social network. Currently, Laura uses her communication book and writes messages to her communication partners to express her desires. Laura has also mastered her instructional routines. Laura's stereotypic or ritualistic behaviours decreased by (70%) at the post- test. Laura's Post implementation independence score on activities performed was 4 (independent). The independence measure is derived from the RLI and consists of a Likert- type scale which measures independence across four standards: (a) substantial support is assigned an independence measure of (1), (b) more than minimal support is assigned an independence measure of (2), (c) minimal support is assigned an independence measure of (3), and (d) no support or independent is assigned an independence measure of (4). Scores are ranked according to the degree and frequency of prompts necessary for an individual to complete an activity.

Bob (Subject 2)

Bob is a 53 year old man who had lived in a large Provincial institution for 40 years. As a result of closing the institution, Bob now lives with one other person in a duplex in a large urban centre. Bob's roommate also moved from the institution.

Bob left the institution in May, 1989. Although Bob's family was contacted by service providers, they did not wish to be involved in planning. Bob had no friends or acquaintances outside of the institution. Information concerning Bob's preferences and abilities was provided by those who knew him from the institution. Bob's community service providers observed his program at the institution during the month transitional phase before Bob was moved from the institution. Bob had not engaged in any community activities during that month.

Bob had behaviour problems, and was observed to pinch, yell, scream, and pull hair. Bob was non-verbal and communicated primarily by gesturing. Those who knew Bob at the institution reported that he liked coloured plastic rings used in preschool toys. Persons working with Bob tied these rings to their belts and Bob held onto them. The rings were used to control his behaviour at the institution.

Step 1 Vision Planning

Bob was referred to the consulting team by his community service provider who provided vocational and residential services to persons with mental disabilities. The initial planning meeting involved the consulting team and Bob's service providers. Bob's service providers formulated the ideal of a meaningful and balanced lifestyle for Bob. A six month process was initiated in which Bob was to be involved in a variety of community and home based activities to determine his strengths and preferences. During the pre- test (March, 1990), 201 community based activities were documented for Bob. These activities included fishing, swimming, shopping, hiking, and recycling. One of Bob's neighbours showed interest in him and brought him jars of home cooked Italian food. Bob visited his neighbours house

once in this month. All of Bob's activities were performed with paid staff who actively promoted his community integration and community connections. Neighbours were invited to come to visit him. Despite these efforts, Bob's Italian neighbour was the only person to visit.

Table 5 shows a typical day of Bob's at the pre- test. Table 6 provides an analysis of Bob's activity patterns and social network at the pre- test (March, 1990), mid- test (August, 1990), and post- test (March, 1991). Bob's main service provider was a progressive organization, which provided an individualized community based program for all persons they served. This was reflected in the program philosophy section of the PQI, as Bob's service providers had a pre- test score of (94%) in this area. Other area and item scores were also reflective of a quality program. Table 7 lists the percentage area and item scores and overall PQI score for Bob's program at the pre- and post- test intervals.

Step 2 Assessing Barriers to Participation

There were no apparent barriers to community participation within Bob's service network. Bob had many opportunities to experience a wide range of activities. The evident barriers were knowledge barriers concerning his learning strengths and personal preferences.

Step-3 Assembling Meaningful Routines and Schedules

By the mid- implementation test (August, 1990) a number of Bob's personal strengths and preferences began to emerge. Bob was working three times per week picking up garbage for the local businesses in his neighbourhood, for approximately 12 hours per week. The negotiated wage was six dollars per hour. Six months after the new program was initiated Bob was reported to have an active balanced schedule, engaging in a total of 250 preferred

Table 6

A Typical Day for Bob (Subject 2)

Pre- Test March, 1990

8:00 Get dressed and have breakfast

9:00 Recycle household items with Greg

10:00 Have a coffee at Arby's

11:00 Go for a walk in the park

12:00 Eat lunch at the park

1:00 Go fishing or crabbing at the public Pier

3:00 Go home and make a snack

4:00 Go for a walk in the neighbourhood

5:00 Eat dinner

7:00 Go swimming at the community pool

9:00 Make lunch for the next day

10:00 Go to bed

Table 7

Category Sum Scores of Activity Patterns for Bob (Subject 2) Pre- Mid- Post- Test

	<u>RLI</u>	Pre	Mid	Post
Total number of activities performed		220	267	385
Total number of different activities performed		22	22	32
Total number of preferred different activities performed		19	22	32
Total number of preferred community activities performed		201	250	224
<hr/>				
	<u>SNAF</u>	Pre	Mid	Post
Total number of people paid to provide service		4	4	4
Total number of activities performed with paid people		220	267	385
Total number of friends		0	0	0
Total number of activities performed with friends		0	0	0
Total number of neighbours/others		1	2	3
Total number of activities performed with neighbour or others		1	16	24
Total number of family members		0	0	0
Total number of activities performed with family members		0	0	0
Total number of co-workers		0	0	0
Total number of activities performed with co-workers		0	0	0

integrated community activities (see table 7, RLI). Bob's social network outside of his paid human service staff had increased by one (see table 7, SNAF). The waitress at The Muffin Shop was interacting and joking with him four times per month on average. Table 9 is a summary of Bob's strengths and preferences, as gathered by his service providers over a six month period.

Step 4 Develop Intervention Strategies

Bob had a varied and active community based schedule; however, several behaviours were jeopardising his community placement. Bob was often awake during the night screaming, yelling, pounding on his walls, and urinating and defecating on his floor. Bob's overnight staff reported that he became agitated in the evening, because he lost one of his toys. In the institution, Bob's access to his toys was controlled, and he was given two toys prior to going to bed. If Bob continued to remain awake his toys were confiscated and he was given sleeping medication. Bob's community service providers did not incorporate this management strategy; instead they allowed Bob free access to his toys and attempted to involve him in a number of functional alternatives, such as a keychain, coin collection, and a wallet. Bob was not interested in these alternatives and began collecting bottle caps, sponges, plastic rings, bread ties, and softballs. Prior to the implementation of intervention strategies, Bob carried over seven items in his hands. Bob's independence measure across activities and routines was 1 (substantial support). Bob had at least one item in his hands at all times. This restricted Bob's ability to fully participate in a range of activities and if Bob lost one of his toys he would yell, scream, and turn over furniture until the item was found. Bob's overnight

Table 8

Percentage Area and Item Scores and Overall Percentage PQI Score for Bob's Program (Subject 2)

	Pre	Post
1. Program Philosophy (items 1-18)	94%	100%
2. Program Design and Student Opportunities for Learning (items 19-27, 33, 34, 36)	69%	88%
3. Systematic instruction and performance evaluation (items 41-64)	64%	79%
4. IPP Development and Parent Participation (items 65-84)	64%	88%
5. Staff Development and Team Collaboration (items 85-86, 89-90, 95-96, 101)	57%	78%
6. Facilities and Resources (items 105-123, were not appropriate for adult services)		
Overall PQI Percentage Score		
	Pre	Post
Overall PQI Score	71%	85%

Table 9

Bob's Strengths and Preferences (Subject 2)

Mid- Test August, 1990

Recreation

likes the outdoors
 hiking
 swimming
 walking in parks
 walking in neighbourhood
 kicking a soccer ball

Community

going to restaurants
 buying coffee at the corner store
 shopping for toiletries
 going to baseball games
 going to the beach

Vocational

likes to pick up garbage
 likes to be active
 likes to be outdoors

Domestic

some cooking
 emptying the dishwasher

General Strengths

gregarious
 good sense of humour
 physically strong
 persistent
 good health

staff reported that sleeping medication had no effect on his behaviour. A medication review was initiated with a pharmacologist. Bob's community service providers conducted an inventory of toys and counted his toys before he left his house. A number of small baskets were placed in Bob's house and he was encouraged to put his toys in these baskets when he was eating, having a bath, and changing his clothes. If Bob lost a toy his service providers neutrally located the toy and focused Bob on the activity being performed. Real objects and clothes items were used to assist Bob in making choices and sequencing his day. Bob's service providers were taught to compile a dictionary of his communicative behaviours. Program staff attended to and responded to these behaviours.

Figure 1 is a graph of Bob's sleeping patterns at pre- and post- intervention, illustrating the percentage of evenings per month that Bob was awake throughout the night, yelling, screaming, and pounding his walls. A multi component behavioral intervention was developed to manage Bob's toy hoarding, screaming, yelling, and pounding of walls (see table 10). Bob's instructional routines were task analyzed and preferred routines were identified which incorporated the functional use of his hands, such as holding onto a garbage bag while working. Bob was encouraged to put his basket of toys within sight while working, swimming, and eating. Once a consistent inventory of toys was established, the toys were systematically reduced in size. Despite Bob's active daily schedule he was restless before bed. It was hypothesised that Bob would benefit from a long walk in the evening. This strategy was implemented in August. Bob's intervention plan was written and program staff held weekly meetings to discuss progress and ensure consistency.

FIGURE 1
% of evenings per month that Bob was awake:
screaming, yelling and pounding on walls.

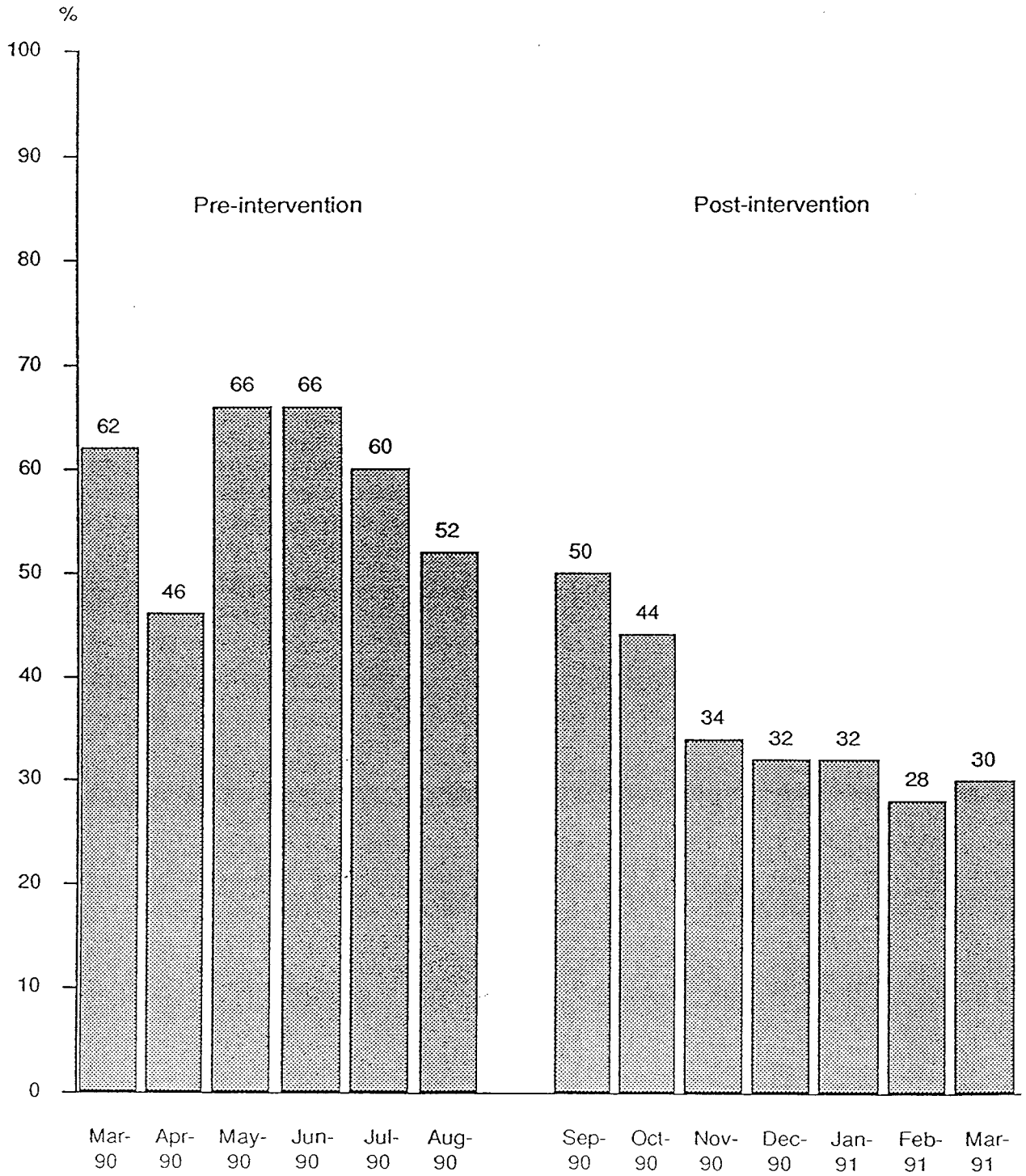


Table 10

Intervention Plan for Bob (Subject 2)
(Behaviours: toy hoarding, yelling, pounding walls)

Ecological Strategies	Program Interventions	Consequences
<ol style="list-style-type: none"> 1. Provide Bob with an inventory system (basket) 2. Increase Bob's physical activity prior to bedtime 3. Provide concrete objects to symbolize next activity (e.g., work clothes to represent work) 4. Place mouldings around bedroom to prevent toys from rolling into closet etc. 	<ol style="list-style-type: none"> 1. Task analyze instructional routines 2. Identify reinforcing incompatible behaviours (e.g., holding onto garbage bag at work, putting toys at side of pool when swimming) 3. Encourage Bob to return new items (e.g., bread ties) 4. Begin reducing the size of Bob's rings (e.g., cut small pieces off of rings to increase functional use of hands) 5. Develop dictionary of Bob's gestural communication and respond to these communicative behaviours. 	<ol style="list-style-type: none"> 1. Respond neutrally to Bob's toy collection and loss of toys. 2. Focus Bob on functional alternatives and reinforce Bob with social attention.

Step 5 Evaluate Effectiveness/Develop Monitoring System

At the post- test (March, 1991) Bob was engaged in a total of 385 activities; the total number of preferred community activities performed was 224. Bob's overall independence measure was 2 (more than minimal support). Bob had mastered the core elements of his work and bathing routine and had an independence measure of 3 (minimal support) in these areas. Bob experienced a substantive increase in the area of personal management. At the pre- test Bob did not engage in any personal management activities. At the post- test Bob partially participated in 20 functional routines, such as making dinner, setting the table, and loading the dishwasher. Bob's independence measure in these routines was 2 (more than minimal support). Bob's social network outside of his paid service workers increased to three persons. Bob performed 24 activities with these persons in this month. The overall PQI score for Bob's program at the post- test was (85%). All area and item scores were higher at the post- test than at the pre- test.

Bob's sleeping medication was discontinued and he slept through the night (70%) of the time. Bob's destructive behaviours at bedtime decreased by (50%) and occurred only three times per month. Bob's toy collection was reduced to one and a half rings and a tennis ball. Bob performs over ten activities without his toys and often leaves them unattended in another room with little anxiety. The toys no longer interfere with his daily routines. Bob independently initiates an activity by presenting his jogging pants, swim suit, or other item of clothing. Table 11 is a typical day for Bob as listed on his weekly schedule at the post-test (March, 1991).

Table 11

A Typical Day for Bob (Subject 2) Post- Test March, 1991

8:00-	Wakeup, choose clothes, get dressed
8:30-	Choose breakfast items, partially participate in making breakfast
9:00-	Gather work materials and sequence day
9:30-	Go to work in community picking up garbage
10:45-	Go to a restaurant in the community for coffee break
11:00-	Return to work
12:00-	Choose restaurant and eat lunch
1:00-	Return to work
2:00-	Go for a jog around the seawall
3:00-	Return home pour bath
3:30-	Choose cologne, get dressed, prepare a snack
4:30-	Assist in choosing and preparing dinner
5:00-	Eat dinner with roommate
5:30-	Help clear the table and load the dishwasher
6:00-	Choose evening activity
6:30-	Go to the corner store for coffee, joke with owner
7:00-	Go to the community centre for a swim and whirlpool
8:00-	Return home and assist in making lunch for workday
9:00-	Go for a walk in the neighbourhood
10:00-	Go to bed

Susan (Subject 3)

Susan is a seven year old girl with autism. She attended an integrated pre-school in 1985-1986 and then received the following two years of her primary school instruction in segregated schools and classrooms. Susan's mother requested that Susan be placed in her neighbourhood school in the regular grade three class. This request was granted by Susan's school district. The consulting team was contacted in the spring of 1990, to assist in a transition and curriculum plan for Susan. The school team was concerned about Susan's seizure disorder, her communication deficits, and her pinching and scratching behaviours.

Step 1 Vision Planning

An initial planning meeting was held at Susan's school in October, 1990. This meeting was attended by Susan's mother, Susan's school team, the school principal, and the consulting team. The school team decided to solicit information from Susan's classmates in an ongoing informal fashion, rather than a planning meeting. The meeting focused on a discussion of integration, developing a network of friends for Susan, and her present schedule. The school team and Susan's mother expressed the following goals for her: (a) make friends, (b) learn to be more comfortable and accepted in the school, and (c) learn and model from her peers.

A review of Susan's schedule revealed that it was identical to her nonhandicapped peers. Table 12 is a daily schedule for Susan in October. Susan participated in a total of 405 activities during this month; of these, 143 were integrated community or school activities. She participated in 45 different activities, however less than (50%) of these activities were preferred activities. Greater than (80%) of Susan's nonpreferred activities were school based activities. Susan's social network outside of her family and paid service providers consisted

Table 12

Susan's (Subject 3) Daily Schedule Pre- Test

8:00	Wakeup, get dressed, choose breakfast, help make breakfast
8:30	Walk to school with mother
8:45	Greet peers on playground, play on swings etc.
9:00	Circle time
9:30	Writing
9:45	Playtime
10:00	Recess
10:30	Math
11:00	Gym
12:00	Lunch
12:30	Recess outside
1:00	Reading and personal journal
1:30	Storytime
2:00	Art
2:30	Music
3:00	Walk with assistant to greet mother
3:30	Walk home make a snack
4:00	Go to the park with mother and sister
5:00	Eat supper, put dishes away
6:00	Play lotto game with sister and mother
7:00	Listen to music, look at books
8:00	Get ready for bed

of five children in her class who consistently greeted her in the morning and played with her in the playground. All interactions with Susan occurred during school hours. Susan did not have any friends visit her home in October.

Table 13 compares Susan's activity patterns and her social network at the pre- test (October, 1990) and post- test (February, 1991). These activities include her daily school schedule. The consultation to Susan's school was intensive, involving 80 hours of intervention during a two week time frame. The interval between the pre- and post- test was not sufficient to apply mid- test measures. Table 14 lists the area and item and overall PQI scores for her school program at the pre- and post- test. The overall PQI score for Susan's school program at the pre- test was (68%). The critical issue addressed at the planning meeting was Susan's lack of participation in a fully integrated school schedule.

Step 2 Assessing Barriers to Participation.

Susan was not confronted with any opportunity barriers in her school program. Susan was the only student with disabilities in her school and she was not pulled out of the classroom for any portion of her day. The school team expressed progressive attitudes towards the process of integration. The evident barrier to Susan's participation was a knowledge barrier concerning her strengths and preferences. Susan's mother observed her in the classroom, and found her resistance and lack of participation to contrast with her behaviours at home. Susan's mother and the school team were tentative about freely exchanging information concerning curriculum design. Full parental involvement in the planning process was a new procedure for all concerned. A second planning meeting was held to review Susan's strengths and capacities and to problem solve curriculum issues. The majority of

Table 13

Category Sum Scores of Activity Patterns for Susan (Subject 3) Pre- Mid- Post- Test

	<u>RLI</u>	Pre	Mid	Post
Total number of activities performed		405	NA	562
Total number of different activities performed		45	NA	53
Total number of preferred different activities performed		20	NA	38
Total number of preferred community activities performed		143	NA	316
<hr/>				
	<u>SNAF</u>	Pre	Mid	Post
Total number of people paid to provide service		4	NA	4
Total number of activities performed with paid people		21	NA	21
Total number of friends		6	NA	8
Total number of activities performed with friends		120	NA	146
Total number of neighbours/others		0	NA	0
Total number of activities performed with neighbour or others		0	NA	0
Total number of family members		3	NA	3
Total number of activities performed with family members		125	NA	140
Total number of co-workers		NA	NA	NA
Total number of activities performed with co-workers		NA	NA	NA

Table 14
Percentage Area and Item Scores and Overall Percentage PQI Score for Susan's
School Program Pre- Post- Test (Subject 3)

	Pre	Post
1.Program Philosophy items 1 through 18 (items 1-5, 7-18)	76%	94%
2. Program design and student opportunities for learning (items 19-20,23-25, 27-40)	80%	93%
3. Systematic instruction and performance evaluation (items 41-64)	56%	70%
4. IPP development and parent participation (items 65-75, 77-79, 81-84)	47%	66%
5 Staff Development and team collaboration (items 85-89, 93-95, 98, 100-104)	66%	77%
6. Facilities and Resources, (items 105-113, 115, 118, 119, 121-123)	86%	86%
Overall PQI Percentage Score		
Overall PQI Score	Pre 68%	Post 81%

information was supplied by Susan's parents. Prior to the second meeting, the importance of parental participation in the planning process was discussed with both the school team and Susan's mother.

Step 3 Assembling Meaningful Routines

The second meeting consisted of an overview of Susan's preferences, strengths, and dislikes (see Table 15). Susan was reported to prefer visual information and had difficulty with extended verbal cues. Susan's favoured activities were swimming, listening to music, playing lotto games, and looking at pictures. Susan's dislikes included math, gym, spelling, and writing exercises.

Step 4 Developing Intervention Strategies

It was hypothesised that Susan's curriculum was contributing to her lack of participation and episodes of scratching and pinching. At the pre- intervention interval of October, Susan participated in (20%) of her integrated classroom instruction. She was sleeping an average of 37 minutes per school day and refused to participate in activities, an average of nine times per school day. These episodes usually occurred at transition times and gym. Pinching and scratching occurred 200 times in October, at an average of 10 per day.

Observations revealed that Susan was most likely to scratch and pinch after she had "flopped" to the ground, refusing to engage in a requested activity. Prior to intervention Susan was physically prompted to engage in these activities. Susan had difficulties sequencing her day, following verbal instructions, and participating in hand over hand seat work. Figure 2 consists of graphs indicating the frequency of (a) "flopping" to the ground refusing instruction, (b) pinching and scratching, and (c) percent participation score at the pre- and post- intervention intervals.

Table 15

Susan's Strengths Preferences and Dislikes (Subject 3)

Strengths and Preferences

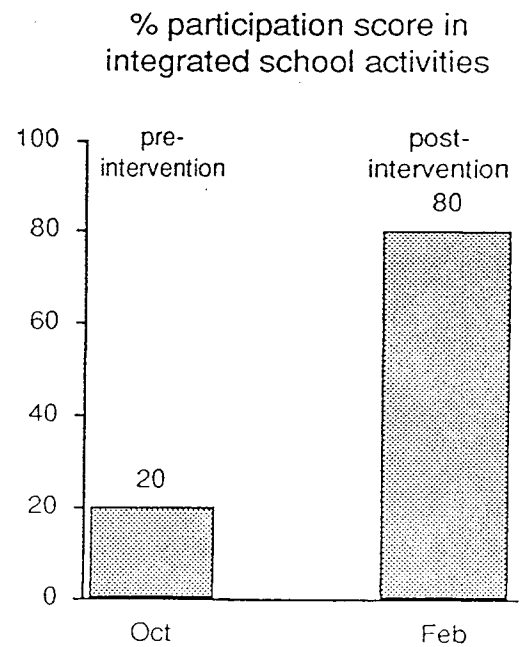
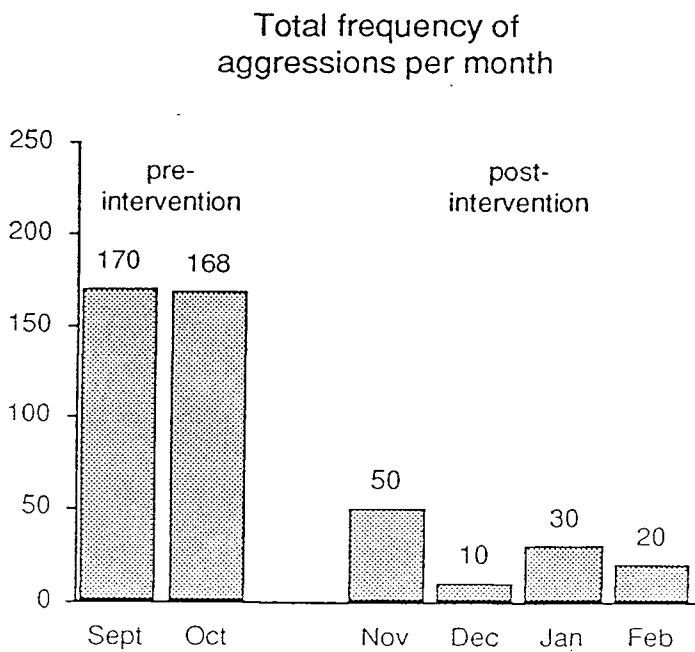
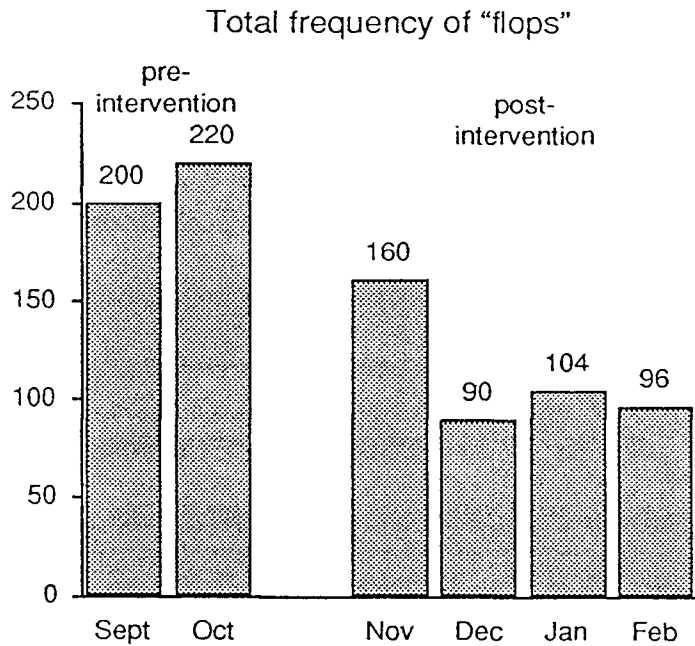
listening to music
 being in control and knowing what comes next
 swimming
 pictures and having information presented visually
 matching games and lotto games
 books and going to the library
 singing and having people sing to her
 familiar surroundings with familiar people and things
 "hanging" out with one or two people
 visiting the activity centre
 riding in a bus or car
 places that are somewhat bright and warm
 noncompetitive slow paced activities

Dislikes

waiting
 new activities
 not knowing what is expected of her
 not having choices
 fast paced competitive games
 movies
 large groups
 noisy crowded places
 homework
 math
 spelling
 physical education
 writing

FIGURE 2

Total frequency of "flops" (refusals), aggressions
per month and percentage participation score
Susan S3



Susan's school team and her peers were assisted in adapting Susan's curriculum and developing communication and behavioral strategies. Susan was given a pictorial sequencing system; pictures of Susan's favourite items were taken and incorporated into her writing and reading exercises. Susan's mother provided the school team with some of Susan's preferred lotto games to use in her free time. Susan's peers were taught to respond to Susan's nonverbal communication, such as pulling her arm away when she did not wish to participate. A picture book was developed and Susan's peers were shown to initiate conversations with Susan using the book.

Susan usually slept between the hours of 10:00-11:00 a.m. It was hypothesised that this was due to Susan's seizure disorder. Susan was offered the choice of sleeping in a designated area at the back of the class at this hour. The length of Susan's activities were also shortened. Consistent precursors to Susan's "flopping" were fidgeting, arching her back, and leaning over. These behaviours were most likely to occur in a large group situation. Susan was prompted to ask for a break when she became agitated. She then proceeded to a small group format with one or two of her peers. Susan and her peers later rejoined the large group and proceeded to the next activity. The school team was instructed to use pictorial cues to signal preferred activities to Susan. Physically prompting Susan to move from one activity to another was discontinued. Table 16 is an overview of the intervention plan developed for Susan; including ecological strategies, and curriculum adaptations applied by her school team.

Step 5 Evaluate Effectiveness/Develop Monitoring System

The consulting team provided a follow up visit to Susan's program at the four month post- implementation interval (February of 1991). All dependent measures were improved

Table 16

Intervention Plan for Susan (Subject 3)

Ecological Manipulations	Curricular Interventions
<ol style="list-style-type: none"> 1. Incorporate preferred activities from home in daily schedule 2. Shorten length of activities 3. Offer choices within daily schedule 4. Incorporate small group instruction within daily schedule 5. Provide pictures to represent sequence of activities 6. Put preferred items out of reach to promote communication 7. Allow for pauses in response time to encourage communication 	<ol style="list-style-type: none"> 1. Identify specific functional learning objectives for academic instruction 2. Utilize pictures of meaningful preferred items in writing and reading exercises 3. Use a variety of functional adapted materials to teach reading and writing skills (ie., personal journal, menu from favoured restaurant) 4. Embed communication goals within naturally occurring daily routines 5. Increase participation systematically 6. Use community based instruction with peers if necessary.

from the pre- test interval of October. Susan participated in 316 preferred integrated activities (see table 13, RLI). The substantive increase in this category was attributed to Susan's participation in school based activities. Susan's percentage participation score for school based activities was (80%) (see figure 2). Susan's social network of friends from school was increased by two. Susan performed 146 activities with these friends (see table 13, SNAF). These included visits to Susan's house after school, "sleep overs", and birthday parties. These were the first integrated, nonschool events, that Susan had ever attended.

Susan's "flopping" behaviours had decreased by (50%) at the post- test. Her scratching and pinching behaviours decreased by (90%) and her spontaneous spoken requests increased by (80%). Her independence measure across activities was 2 (more than minimal support). The school team held monthly review meetings with Susan's mother and continued to reference goals and objectives to Susan's integrated daily schedule.

Carol (Subject 4)

Carol is a seven year old girl with sanfilippo syndrome, mucopolysaccharidosis III (MPS III). Carol has aggressive behaviours, is hyperactive, and requires substantial support in all areas of her daily living. Carol attended her neighbourhood school in the 1988-1989 school year. A diagnosis of sanfilippo syndrome had not been made yet. Prior to the onset of this illness, she had age-appropriate language development and participated in the regular school curricula. In October, 1989, it was observed that her language and self care skills had rapidly deteriorated and she was aggressive towards her peers. The diagnosis of sanfillippo syndrome was made at this time. Also, the feasibility of maintaining Carol at home and at school was raised by Carol's professional team. Due to Carol's aggressive behaviours, she was moved from her neighbourhood school and placed in a self contained padded room, previously used by hearing impaired students, in an elementary school across town.

A referral to the consulting team was initiated by Carol's social worker and her parents. The family sought guidance in the areas of curriculum planning, behaviour management strategies, ecological strategies, communication strategies, and "survival" strategies. The situation was described as urgent.

Step 1 Vision Planning

An initial planning meeting was held at Carol's home in November, 1989. The meeting was attended by the consulting team, Carol's parents, and her sister. The meeting focused on Carol's existing and desired future schedule of activities. A review of Carol's existing schedule revealed a considerable discrepancy between the desired and actual schedules. Carol's parents identified a range of preferred activities in which they hoped Carol could participate. These included swimming at the community pool, walking in trails behind her home, playing in the neighbourhood park, eating at restaurants, and participating with her peers at school. Prior to planning and intervention, the only preferred community based

activity that Carol engaged in was a walk in her neighbourhood. The majority of Carol's schedule consisted of instruction in a self contained classroom and in home activities with her parents and sister. Carol's social network was comprised of people paid to be with her, and her family.

It was evident that there were substantive opportunity barriers impeding Carol's community and school integration. The meeting ended with a resolution to identify and remediate these barriers. Table 17 lists Carol's daily schedule at the pre- test (November, 1989). Table 18 lists Carol's activity patterns and social network at the pre- test, mid- test (August, 1990) and the post- test (February, 1991). Table 19 lists the area and item scores and overall PQI score for Carol's educational program at the pre- and post- test. The overall PQI score for Carol's educational program in November was (43%).

Step 2 Assessing Barriers to Participation

In November, 1989, Carol's professional support network consisted of a Provincial consulting team which provided services to her school district, the author's consulting team which provided services to her family and social service providers, and her physician. A review of program plans, medical files, and interviews with relevant personnel revealed that the primary data used for educational planning was an analysis of developmental milestones for children with sanfilippo syndrome. The author's consulting team conducted a literature search of the Medline data base regarding sanfillippo syndrome from 1966 to 1989. This review reported that a lack of disseminated knowledge on the natural history of the syndrome has limited the ability of health professionals to counsel parents in the day-to-day management of children with MPS III (Nidiffer & Kelly, 1983).

Table 17

Carol's Daily Schedule Pre- Test November, 1990

7:00	Get dressed and have a bath (bathed and dressed by parents)
7:30	Eat breakfast (fed by mother or father)
8:00	Get ready for school (dressed by mother or father)
8:30	Drive to school with mother
9:00	Proceed directly to self-contained classroom
9:30	Wait for other children to leave playground
9:40	Play in playground with teaching assistant
10:00	Return to self-contained class for seatwork (play with soft toys, puzzles, plastic assembly toys, wooden hammer and bench etc.)
10:30	Go to the gym if it is empty and run around with teaching assistant
11:00	Return to seatwork
12:00	Eat lunch in self-contained room with teaching assistant
1:10	Wait for children to leave playground
1:15	Play in the playground with teaching assistant
1:45	Return to class for seatwork
3:30	Wait for students to go home, play in the playground with teaching assistant (the teaching assistant was also hired by the social services ministry to provide support to the family, both the assistant and Carol remained at the school until 6:00 p.m.)
4:30	Play in self-contained classroom
6:00	Go home with mother
6:30	Eat supper (fed by parents)
7:00	Play in house with sister and family
7:30	Watch a video
8:00	Get ready for bed (bathed and dressed by parents)
8:30	Go to bed
10:00	Typically fell asleep between 10:00 and 11:00 p.m

Table 18

Category Sum Scores of Activity Patterns for Carol (Subject 4) Pre- Mid- Post- Test

	<u>RLI</u>	Pre	Mid	Post
Total number of activities performed		172	391	295
Total number of different activities performed		11	21	18
Total number of preferred different activities performed		6	19	16
Total number of preferred community activities performed		19	90	63
	<u>SNAF</u>	Pre	Mid	Post
Total number of people paid to provide service		2	9	9
Total number of activities performed with paid people		80	190	165
Total number of friends		0	5	8
Total number of activities performed with friends		0	30	15
Total number of neighbours/others		0	0	0
Total number of activities performed with neighbour or others		0	0	0
Total number of family members		3	5	3
Total number of activities performed with family members		92	152	130
Total number of co-workers		NA	NA	NA
Total number of activities performed with co-workers		NA	NA	NA

Table 19

Percentage Area and Item Scores and Overall Percentage PQI Score for Carol's
Program (Subject 4) Pre- Post- Test

	Pre	Post
1. Program Philosophy (items 1-5, 7-18)	41%	65%
2. Program Design and Student Opportunities for Learning (items 19-20, 23-25, 27-40)	38%	63%
3. Systematic Instruction and Performance Evaluation (items 41-64)	47%	60%
4. IPP Development and Parent Participation, (items 65-75, 77-79, 81-84)	25%	70%
5 Staff Development and Team Collaboration (items 85-89, 93-95, 98, 100-104)	50%	55%
6. Facilities and Resources, (items 105-113, 115, 118, 119, 121-123)	57%	62%
Overall PQI Percentage Score		
	Pre	Post
Overall PQI Score	43%	63%

However, Nidiffer and Kelly (1983) noted that behavioral techniques had shown promise in managing hyperactivity, aggression, and property destruction with these children.

The author's consulting agency contacted the school based consulting team to review program plans for Carol and to discuss her educational placement. Recommendations by the school based team reported that a self-contained classroom was an appropriate placement for Carol. The school based consulting team also supported the option of having Carol receive home based educational services in her basement.

The director of special services of Carol's school district was contacted by the author's agency. This individual reported that his decisions were influenced by the recommendations of his professional consultants, and that any program plans would need validation by these individuals. The author's consulting team met with Carol's parents in January and discussed the professional dynamics that appeared to be influencing Carol's educational placement. A formal request to have Carol registered in her neighbourhood school for the following school year was initiated. Carol's parents met with her school team in February, 1990, to discuss this plan. This meeting was attended by Carol's parents, the school based consulting team, the director of special services, the principal of Carol's neighbourhood school, and several persons from Carol's social service system. The school based team was reported to have reservations about this plan and requested a meeting with the author's consulting team. This meeting was arranged for March. Telephone conversations with the school based team revealed that there were substantive concerns about the integration plan. The author's consulting agency therefore contacted two recognized experts in the area of persons with severe disabilities. Several meetings were held with these experts prior to the meeting. A validation of the integration plan was established. One of these experts accompanied the author to the planning meeting with the school team. The integration plan was discussed at this meeting and it was agreed that the school team would initiate an integration plan, if it

could be shown over the summer months that interactive activities were mutually beneficial to Carol and her peers.

Step 3 Assembling Meaningful Routines

Given Carol's dramatic decrease in self care skills and her increased aggressive behaviours, several staffing and environmental changes had occurred since November, 1989. Carol's family received respite services once per month and a summer program that required eight hours of staffing was made available. The author's consulting team developed a program plan and trained the staff. Despite the funding for Carol's summer program, there were difficulties in recruiting staff to work with her. In June, two program staff were hired. Observations and interviews with parents suggested that Carol required a large percentage of unrestricted "high energy" activities, such as running in the woods, swimming, and running in the park. Carol was also reported to prefer these high energy activities in the afternoon. A summer schedule was developed for Carol that incorporated a range of preferred low, moderate, and high energy activities.

A list of Carol's old friends from her neighbourhood school was compiled by her parents. The parents of these five children were contacted to attend a meeting to discuss Carol's isolation and means of reuniting Carol with her peers. All five parents agreed to have their children participate in activities with Carol. A subsequent meeting was held with the children to discuss strategies to involve Carol in a range of motivating activities and ways to manage her aggressions.

Table 20 lists Carol's preferred activities in August, 1990. Table 21 is a daily schedule of Carol's summer program at the mid- test of August. At the mid- test Carol participated in 90 preferred community based activities (see Table 18, RLI). These included swimming at the local lake, eating at restaurants, going to the store, and playing at the arcade. Thirty of these

activities were performed with a peer (see table 18, SNAF). These were substantial increases from the pre- test.

Step 4 Developing Intervention Strategies

Carol's independence measure in all activities prior to intervention was 1 (substantial support). The following teaching objectives were developed: (a) teach Carol to independently eat a bowl of yogurt; (b) teach Carol to independently walk one block; (c) teach Carol to associate real objects with preferred activities; (d) teach Carol to choose a preferred food item at the store; and (e) teach Carol to wait in line, order food, and feed herself finger food at a restaurant. Carol's service providers were taught to develop task analyses and to systematically fade and shape their instructional cues (Billingsley & Romer, 1983). A multicomponent behaviour management strategy was developed, which included placing safety locks on cupboards, minimizing hard toys, and giving Carol access to high energy activities. Real objects were used to signal an activity to Carol and allow for choice making. Carol's peers were taught to shake Carol's hand when she approached them. This strategy interrupted her hitting, which was her typical greeting. Prior to intervention Carol's service providers and parents were unable to walk with her in the neighbourhood. Carol was reported to run away, flop on the ground, and eat objects from the street. She was consequently placed in a large stroller when she was in the community. After one month of systematic instruction, Carol was able to walk to the park (independence measure 3, more than minimal support).

After one month of similar instruction, Carol was also able to eat a bowl of yogurt with a spoon. In February of 1990 a report noted that Carol was, "aggressive to all persons, in all environments". In August, Carol's aggressive behaviours were reduced by (70%) and she was mostly aggressive to smaller children. These aggressions usually occurred when the smaller child was in close proximity, or when Carol was in a confined space. When Carol

Table 20

Carol's Preferred Activities August, 1990

<u>High Energy Activities</u>	<u>Moderate Activities</u>
Swimming	Eating at Mcdonalds
Bike riding	Buying yogurt at the grocery store
Hiking	Playing in the basement
Running in the park	
Running on the beach	
Jumping on a trampoline	
<u>Low Energy Activities</u>	
Eating	
Having a bath	
Listening to music	
Watching videos	

Table 21
Carol's Daily Schedule Mid- Test August, 1990

8:00	Wake up - partially participate in dressing and bathing
8:30	Eat breakfast - choose breakfast items
9:00	Walk to school playground with sister or peer
10:00	Return home for snack
11:00	Play in backyard with sister or peer
12:00	Go for a picnic or out to a restaurant for lunch
1:00	Go swimming at the lake
2:30	Go to the grocery store and buy yogurt
3:00	Eat yogurt in backyard with sister and or peer
3:30	Walk to the park
4:30	Play in the basement or backyard
6:00	Eat dinner
6:30	Watch a video
7:00	Go to the park with sister, mother and father
8:00	Get ready for bed

was allowed to run freely in the park, she was seldom aggressive to the other children.

Carol's schedule and instructional programs were written and videotaped. A meeting was held in the following fall with the school team. An itinerant teacher had been hired for Carol, and after reviewing the progress reports and videotapes, the school team agreed to enroll Carol in her neighbourhood school. It was further agreed that Carol required a slow transition to her integrated school environment. Lunch, recess, and gym were identified as the initial integration points. The remainder of Carol's day was to be spent in the community.

Step 5 Evaluate Effectiveness/Develop Monitoring System

At the post- test in February, 1991, Carol performed 63 integrated community and school activities (see Table 18, RLI). These activities included a gym class, and swimming with two peers from her school. She had eight friends and participated in 15 activities with them during this month (see Table 18, SNAF). All areas measured were substantially higher at the post- test than at the pre- test. The overall PQI score for Carol's educational program at the post-test was (63%), and all area and item scores were higher than at the pre- test (see Table 19, PQI). There were communication difficulties between the teaching assistants and Carol's school team. These were solved by having the itinerant teacher reference all teaching objectives to integrated school and community environments. Carol's friends were also included in program monitoring and feedback.

Carol's aggressions were higher at the post- test than at mid- test but were (50%) lower than at the pre- test. It was thought that the winter weather and the decrease in strenuous options were a contributing factor. Carol's aggressions were lowest during gym and swimming with her peers. She was seldom aggressive towards her peers during these activities. Carol maintained her ability to eat a bowl of yogurt by herself. She was choosing snacks at the corner store and regularly ate a bag of french fries at a local restaurant with

minimal support. Walking in the neighbourhood continued to require substantial support.

Table 22 is Carol's daily schedule in February, 1991.

Table 22
Carol's Daily Schedule Post- Test February, 1991

8:00	Wake up, partially participate in bathing and grooming Get dressed Go downstairs for breakfast with sister
8:30	Eat breakfast Feed self with spoon (in presence of adult, required prompts)
9:00	Go to playroom with sister Play with sister
9:30	Walk to neighbourhood school Go to adapted gym class with five peers Jump on the trampoline Play tag with the kids
10:30	Go to the school playground for recess with peers Play on the adventure playground explore
11:00	Go to fast food restaurant or grocery store to buy lunch items (sometimes with peers from school)
12:00	Eat lunch at home or with peers at school
1:00	Go to the park or school playground
2:00	Go home to make snack
3:00	Play with sister in playroom
4:00	"Hang out" with family upstairs
5:00	Eat dinner
6:00	Play with sister and family
7:00	Play with sister in play room
8:00	Get ready for bed
8:30	In bed

DISCUSSION

The results of this study suggested that the Life Style Development Process (LDP) had a positive impact on the subjects activity patterns, overall program, and skill acquisition. Further, these gains were maintained at the post- test. All four subjects were engaged in a greater number of integrated activities at the mid- test and post- test, than at the pre- test. Three of the four subjects experienced greater than 200% gains in the number of preferred integrated activities performed at the post- test.

The two adult subjects in this study were engaged in the first integrated work opportunities of their lives. Increases in the number of preferred activities engaged in by each subject was reflective of the strengths and preference list compiled in steps one and three of the LDP. This extends the data reported by Mount (1987) concerning the development of lifestyle plans that are based on an individuals strengths and capacities rather than their deficits.

All four subjects experienced increases in their social network outside of their paid service network. All subjects also performed a greater number of integrated activities with people outside of their paid service network at the mid and post- test, compared to the pre- test. Although the importance of friendships was discussed in all of the planning meetings only Carol (subject 4) had a planning meeting specifically devoted to increasing her social network. At the pre- test, Carol's friends had ceased visiting her and had lost contact with her. Some of these children thought that Carol had died. The planning meeting for Carol contributed to the increase in friends. These data support the facilitative process described by Forest and Lusthaus (1987). This process involves a planning meeting with a core group of peers to develop strategies to increase participation of the person with a disability in a range of normalised activities. Susan's (subject 3) circle of friends increased without any formal intervention, and it is probable that the integrated placement alone was the contributing factor.

Bob's (subject 2) social network outside of his paid staff had increased by two persons at the post- test. However, these activities were peripheral at best. Efforts were made by Bob's staff to increase his community connections and network of friends. Building Bob's social network remains a challenge. The identification of the importance of a rich social life for persons with disabilities is just emerging probably because there is little empirical information to guide families, service providers, and researchers in this area (Kennedy et al., 1990). Barrera (1986) suggested that the service delivery system and general community do not have a clear understanding of what defines social life, much less effective measurement systems for these constructs. However, recent empirical investigations have focused on identifying people who are important to a person with a disability and measuring the type and kind of activities engaged in with those persons (Kennedy et al., 1990). These measures were reflected in the four case histories of this study.

All four subjects' programs reflected a greater number of validated "most promising practices" at the post- test than at the pre- test. The overall percentage gains from pre- to post- test ranged from (13-43%). The lowest pre-test scores were reported in the most segregated programs (subject 1 and subject 4) which was consistent with the findings of Hunt et al. (1989) on the impact of integrated placements on the quality of program plans.

Three technical components were addressed in the LDP. These were non-aversive behaviour management strategies, augmentative and alternative communication strategies, and task analyzed instructional routines. All four subjects' behaviour problems identified at the referral phase were positively affected at the post- test. The multi component, lifestyle referenced strategies, were consistent with the approach advocated by Horner (1991). The communication strategies reflected the non exclusionary approach identified by Mirenda et al. (1990). Instructional routines identified for each subject were age appropriate, functional and were taught in the environments in which they were needed. Hunt et al. (1990) identified

these three criteria as important for developing quality instructional programs for persons with severe disabilities. All four subjects experienced greater community/school participation after the implementation of instructional, communication, and behavioral strategies. These findings suggest that specific validated teaching strategies enhance the lifestyle planning process by providing individuals with the opportunity to increase their competence in integrated activities, and to experience greater autonomy by making choices throughout their daily schedules.

All of the cases described in this study reported positive results. Many persons referred to the consulting teams did not experience such results. Most of these individuals were served in the highly restrictive ends of the LRE continuum, such as day activity centres, and large pre-vocational training centres. In such cases, the involvement with the consulting team was usually terminated by the referring agency. Agencies providing restrictive and segregated services tended to disagree with the lifestyle approach and references to lifestyle quality for persons with severe disabilities. Common responses to recommended program changes were, "too idealistic", "unrealistic", and "too costly". The referring agency typically framed the problem as resting with the individual with a disability. These organizations were reluctant to accept program recommendations which suggested that many of the problems could be interpreted as systemic. Systemic change and improved quality of service by means of the consultant process is difficult to achieve and requires further research and refinement if this goal is to be reached (Ziarnik and Bernstein, 1988).

A selection criterion for subjects involved in this study was completion of all steps of the LDP. As completion was voluntary and relied substantially on the discretion of service agencies or families to commit to the process, selection bias limits the degree to which the findings can be generalized. Also, the small sample size limits the generalization of the findings, although the study attempted to minimize the selection bias by collecting data at

four separate sights, and four different program placements within the LRE continuum. Finally, a number of data collection techniques such as video tapes, valid quantitative measures, direct observation, and interviews were used in an attempt to control experimenter bias (Borg & Gall, 1989). The major threat to the internal validity of this study was programmatic change that occurred outside of the LDP process. To minimize this threat, extensive placement and program histories were compiled, and measurement occurred at intervals which coincided with the application of specific steps of the LDP.

The present study extends the previous literature on lifestyle planning models for persons with severe disabilities. This study indicated that a lifestyle planning model that is systematic in design and is based on methods derived from previous research can be delivered to both children and adults in a variety of settings within the LRE continuum. This study also indicated that the lifestyle planning process is enhanced by including specific steps which address valid teaching methods for persons with severe disabilities. Previous studies (e.g., Mount, 1987; O'Brien, 1987; Vandercook et al., 1989) did not specifically address valid teaching components as a necessary part of the process.

Implications for Further Research

Further research is needed in the identification of individual strengths and abilities and the role of teaching technologies in the implementation of lifestyle planning. Nevin and Thousand (1986) reported that cognitive assessment and instructional remediation have promising implications for educational practices involving students with severe disabilities. Until the identification of specific learning strengths and styles becomes an integral component of lifestyle planning, the assumption that the process truly involves a persons strengths remains uncertain. This study concentrated on three areas of technical assistance that have been identified in the research as promising practices for persons with severe disabilities. The areas of nonaversive behaviour management, augmentative and alternative

communication, and task analyzed instructional routines are a small set of a much broader area of promising teaching techniques which have potential for increasing learning and functioning of persons with disabilities (Nevin and Thousand, 1986). Nevin and Thousand (1986) indicate that the gap between what is researched best practice and what is currently being practised is considerable. It is therefore necessary to identify and research appropriate and efficacious training models to ensure that best educational practices are actually being applied in day to day instruction.

Despite recent attention to integrating persons with disabilities into the mainstream of society the organizational system for achieving this goal remains the LRE continuum. This continuum has been shown to be the most serious threat to achieving this goal (Taylor, 1988). Two subjects in this study were placed in highly restrictive ends of the LRE continuum prior to implementation of the LDP. In both instances the specific identification of the restrictive placement, and presentations of integrated placements for persons with severe disabilities by recognized experts in the field, appeared to influence the decision to move these subjects to integrated placements. Research on ways and means to supplant the LRE continuum is required.

Recent research attention has focused on the merger of special and regular education technologies to create quality education for all students (Stainback, Stainback, & Forest, 1989). The LDP and other lifestyle planning models are highly individualized and attempt to identify personal preferences and capacities as the foundation for planning and programming. The application of this model to regular students appears to have theoretical benefit.

In conclusion, the results of this study demonstrated that the LDP positively affected the degree and kind of integrated activities performed by four persons with severe disabilities. This finding adds to the growing body of research that has investigated the applications of

lifestyle planning for persons with severe disabilities. Also, this study demonstrated that the implementation of valid teaching technologies enhanced the abilities of all four persons to make choices and to participate in valued community and school activities. Finally, the results of this study indicated that two subjects experienced substantive opportunity barriers to participation which required extensive intervention. In these cases, a referral for consultative services was precipitated by a crisis and the LDP was applied reactively. The most expedient application of the LDP occurred when the process was applied proactively to facilitate an integration plan for Susan (subject 3). In this case planning and implementation focused on Susan's strengths and preferences and necessary teaching strategies to increase her participation in fully integrated school activities. Positive results were reported after one month of intervention. Also, Susan's school team reported that experiences with Susan's curriculum had helped them with curriculum changes for other nonhandicapped students. This result supports the findings that early, integrated, and individualized education, promotes quality education for all students.

REFERENCES

- Ackoff, R., & Emery, F. (1972). On purposeful systems. London: Tavistock.
- Barrera, M. (1986). Distinctions between social support concepts, measures, and models. American Journal of Community Psychology, 14, 413-445.
- Bellamy, T., Rhodes, L., Bourbeau, P., & Mank, D. (1986). Mental retardation services in sheltered workshops and day activity programs: Consumer benefits and policy alternatives. In F. R. Rusch (Ed.), Competitive employment issues and strategies (pp. 257-271). Baltimore: Paul H. Brookes.
- Biklen, D. (1982). The least restrictive environment: Its application to education. In G. Melton (Ed.), Child and youth services (pp. 121-144). New York: Haworth.
- Billingsley, F. (1984). Where are the generalized outcomes? The Journal of the Association for Persons with Severe Handicaps, 9, 186-192.
- Billingsley, F. F., & Romer, L. T. (1983). Response prompting and the transfer of stimulus control: Methods, research, and a conceptual framework. Journal of The Association for Persons with Severe Handicaps, 8 (2), 3-12.
- Blatt, B. (1969). Exodus from pandemonium. Boston: Allyn & Bacon.
- Block, J. (1974). Schools society and mastery learning. New York: Holt, Rinehart, & Winston.
- Bloom, B. (1980). The new direction in education. Alternative variables. Phi Delta Kappa, 61, 382-385.
- Bolles, R. (1984). The three boxes of life: A guide to life planning. Berkeley, CA: Ten Speed Press.
- Borg, W. R., & Gall, M. D. (1989). Educational Research. New York: Longman.

- Braddock, D., Hemp, R., & Fujiura, G. (1986). Public expenditures for mental retardation and developmental disabilities in the United States: State profiles (2nd ed.) Chicago: University of Illinois.
- Browder, D. M., & Stewart, K. L. (1982). Curriculum development for the severely handicapped student. Journal of Special Education Technology, 5 (3), 43-52.
- Brown, L., Falvey, M., Vincent, L., Kaye, N., Johnson, F., Ferrara-Parrish, P., & Gruenewald, L. (1980). Strategies for generating comprehensive, longitudinal, and chronological-age-appropriate individualized education programs for adolescent and young -adult severely handicapped students. The Journal of Special Education, 14 (2), 200-215.
- Brown, L., Ford, A., Nisbet, J., Sweet, M., Donnellan, A., & Gruenewald, L. (1983). Opportunities available when severely handicapped students attend chronological age appropriate regular schools. The Journal of the Association for Persons with Severe Handicaps, 8 (1), 16-24.
- Brown, L., Nietupski, J., & Hamre-Nietupski, S. (1976). Criterion of ultimate functioning. In M. A. Thomas (Ed.), Hey don't forget about me: Education's investment in the severely, profoundly and multiply handicapped (pp. 2-15). Reston, Va: Council for Exceptional Children.
- Brown, L., Nisbet, J., Ford, A., Sweet, M., Shiraga, B., York, J., & Loomis R. (1983). The critical need for nonschool instruction in educational programs for severely handicapped students. Journal of the Association for the Severely Handicapped, 8, 71-77.
- Churchman, C. W. (1982). Thought and wisdom. Seaside, CA: Intersystems Publications.
- Crystal, J., & Bolles, R. (1974). Where do I go from here with my life? Berkeley, CA: Ten Speed Press.
- Cutler, B. C. (1981). Unraveling the special education maze. Champaign, Il: Research Press.

- Darling, R. B. (1983). Parent-professional interaction: The roots of misunderstanding. In M. Seligman (Ed.), The family with a handicapped child: Understanding and treatment (pp. 95-121). New York: Grune & Stratton.
- Darling, R. B., & Darling, J. (1982). Children who are different. St. Louis: C.V. Mosby.
- Donnellan, A. M., & Mirenda, P. L., (1984). Issues related to professional involvement with families of individuals with autism and other severe handicaps. The Journal of the Association for Persons with Severe Handicaps, 9 (1), 16-25.
- Dudley, M., & Curtis, C. (1985). Perceptions of the usefulness of the IEP by teachers of learning disabled and emotionally disturbed children. Psychology in the Schools, 22 (1), 65-67.
- Dunn, L.M. (1968). Special education for the mildly retarded- Is much of it justifiable? Exceptional Children, 35, 5-22.
- Dybwad, G. (1964). Challenges in mental retardation. New York: Columbia University Press.
- Emery, F., & Emery, M. (1976). A choice of futures. Lieden, The Netherlands. Martinus Nijhoff.
- Evans, I. M., & Meyer, L. H. (1985). An educative approach to behaviour problems. Baltimore: Paul H. Brookes.
- Falvey, M. A. (1986). Community- based curriculum: Instructional strategies for students with severe handicaps. Baltimore: Paul H. Brookes.
- Feurstein, R., Rand, Y., & Rynders, J. E. (1988). Don't accept me as I am: Helping retarded people to excel. New York: Plenum.
- Forest, M. (1987). Start with the right attitude. Entourage, 2, 11-13.
- Forest, M., & Lusthaus, E. (1987). The Kaleidoscope: A challenge to the cascade. In M. Forest (Ed.), More Education/integration (pp. 1-16). Toronto, Ontario: G. Allan Roeher Institute.

In M. Forest (Ed.), More Education/integration (pp. 1-16). Toronto, Ontario: G. Allan Roeher Institute.

Froh, R., & Muraki, E. (1980). Modification and discontinuance of mastery learning strategies. Paper presented at the annual meeting of the Midwestern Educational Research Association, Toledo, OH.

Gardner, J. (1980). Interdisciplinary team process and individualized program planning. In J. Gardner (Ed.), Program issues in developmental disabilities (pp. 107-125). Baltimore: Paul Brookes.

Gerber, P. J., Banbury, M. M., Miller, J. H., & Griffin, H. C. (1986). Special educators' perceptions of parental participation in the individual education plan process. Psychology in the Schools, 23, 158-163.

Gharajedaghi, J. (1984). On the nature of development. Human Systems Management, 4, 163-170.

Gilliam, J. E., & Coleman, M. C. (1981). Who influences IEP committee decisions? Exceptional Children, 47, 642-644.

Hall, R. V., & Copeland, R. (1972). The responsive teacher model: A first step in shaping school personnel as behaviour modification specialists. In F. Clark, D. Evans, L.

Hammerlynck (Eds.), Implementing behaviour programs for schools (pp. 125-131). Champaign, IL: Research Press.

Hall, R. V., Lund, D., & Jackson, D. (1986). Effects of teacher attention on study behaviour. Journal of Applied Behaviour Analysis, 1, 1-12.

Hammill, D. D., & Bartel, N. R. (Eds.). (1975). Teaching children with learning and behaviour problems. Boston: Allyn and Bacon.

Haring, N., Lovitt, J., Eaton, M., & Hansen, C. (1978). The fourth R: Research in the classroom. Columbus, OH: Merrill.

- Hehner, B. (1980). Blissymbols for use. Toronto, Ontario: Blissymbolics Communication Institute.
- Hermay, T. (1987). An investigation into the team member perceptions of communication in the individual program planning system. Calgary (Alberta): Vocational and Rehabilitation Research Institute.
- Hitzing, W. (1987). Community living alternatives for persons with autism and severe behaviour problems. In D. J. Cohen & A. Donnellan (Eds.) Handbook of autism and pervasive developmental disorders (pp. 396-410). New York: John Wiley.
- Horner, R. H. (1991). The future of applied behaviour analysis. In L. Meyer, C. Peck, L. Brown, (Eds.), Critical issues in the lives of people with severe disabilities. Baltimore: Paul H. Brookes.
- Hunt, P., Goetz, L., & Anderson, J. (1986). The quality of IEP objectives associated with placement on integrated versus segregated school sites. The Journal of The Association of Persons with Severe handicaps, 11, 125-130.
- Janney, R. E., & Meyer, L. H. (1990). A consultant model to support integrated educational services for students with severe disabilities and challenging behaviors. Journal of the Association for Persons with Severe Disabilities, 15, 186-199.
- Johnson, D. W., Maruyama, G., Johnson, R., Nelson, D., & Skon, L. (1981). The effects of cooperative, competitive, and individualistic goal structures on achievement: A meta-analysis. Psychological Bulletin, 89, 47-62.
- Kaye, N. L., & Aserlind, R. (1979). The IEP: The ultimate process. The Journal of Special Education, 13, 136-143.
- Kennedy, C. H., Horner, R. H., & Newton, S. J. (1990). The social networks and activity patterns of adults with severe disabilities: A correlational analysis. Journal of The Association for Persons with Severe Handicaps. 15, 86-90.

- Kennedy, C. H., Horner, R. H., Newton, S. J., & Kanda, E. (1990). Measuring the activity patterns of adults with severe disabilities using the resident lifestyle inventory. Journal of The Association for Persons with Severe Handicaps, 15, 79-85.
- LaVigna, G. W., & Donnellan, A. M. (1987). Alternatives to punishment: solving behaviour problems with non-aversive strategies. New York: Irvington Press.
- Lewis, M. (1982). The social network systems model: Toward a theory of social development. In T.M. Fields, A. Huston, H.C. Quay, L. Trowl, & E. Finely (Eds.), A review of human development (pp. 180-214). New York: Wiley Interscience.
- Lilly, S. (1970). Special education: A tempest in a teapot. Exceptional Children, 32, 43-49.
- Lynch, E., & Beare, P. L. (1990). The quality of IEP objectives and their relevance to instruction for students with mental retardation and behavioral disorders. Remedial and Special Education, 11, 48-55.
- Lyon, S., & Preis, A. (1983). Working with families of severely handicapped persons. In M. Seligman (Ed.), The family with a handicapped: Understanding and treatment (pp. 203-232). New York: Grune & Stratton.
- Meyer, L. H., Eichinger, J., & Park-Lee, S. (1987). A validation of program quality indicators in educational services for students with severe disabilities. Journal of The Association for Persons with Severe Disabilities, 12, 251-263.
- Mirenda, P., Iacono, T., & Williams, R. (1990). Communication options for persons with severe and profound disabilities: State of the art and future directions. Journal of The Association for Persons with Severe Handicaps, 15, 3-21.
- Mount, B. (1987). Personal futures planning: Finding directions for change (Doctoral dissertation, University of Georgia). Ann Arbor, MI: UMI Dissertation Information Service.

- Mount, B., & Zwernik, K. (1988). It's never too early, it's never too late. St. Paul, MN: Metropolitan Council, Publication No. 421-88-109.
- Nevin, A., & Thousand, J. (1986). What the research says about limiting or avoiding referrals to special education. Teacher Education and Special Education, 9, 149-161.
- Nidiffer, F. D., & Kelly, T. E. (1983). Developmental and degenerative patterns associated with Sanfilippo Syndrome. Journal of Mental Deficiency, 27, 185-203.
- O'Brien, J. (1987). A guide to life-style planning. In B. Wilcox & G.T. Bellamy (Eds.), A comprehensive guide to The Activities Catalog. Baltimore: Paul H. Brookes.
- O'Brien, J., & Lyle, C. (1987). Framework for accomplishment. Decatur, GA: Responsive Systems Associates.
- Rosenburg, S., & Beukelman, D. (1987). The Participation Model. In C. A. Costin (Ed.), Proceedings of the National Planners Conference on Assistive Device Service Delivery (pp. 159, 161). Washington, DC: RESNA, The Association for the Advancement of Rehabilitation Technology.
- Sailor, W., & Guess, D. (1983). Severely handicapped students: An instructional design. Boston: Houghton Mifflin.
- Sailor, W., & Haring, K. (1988). Annual report: Year 1. San Francisco State University, Department of Special Education, California Research Institute on Placement of Students with Severe Disabilities.
- Salvia, J., & Ysseldyke, J. E. (1985). Assessment in Special and remedial education. Boston: Houghton Mifflin.
- Schalock, R. L. (1983). Services for developmentally disabled adults. Baltimore: University Park Press.
- Seigel-Causey, E., & Guess, D. (1989). Enhancing non-symbolic communication interactions among students with severe disabilities. Baltimore: Paul H. Brookes.

- Seligman, M. (1979). Strategies for helping parents of exceptional children. New York: The Free Press.
- Slavin, R. (1984). Review of cooperative learning research. Review of Educational Research, 50, 315-342.
- Snell, M. E. (Ed.). (1983). Systematic instruction of the moderately and severely handicapped (2nd ed.) Columbus, OH: Charles Merrill.
- Stainback, S., Stainback, W., & Bunch, G. (1989). Introduction and historical background. In S. Stainback, W. Stainback, and M. Forest, (Eds.), Educating all students in the mainstream of regular education (pp. 3-13). Baltimore: Paul H. Brookes.
- Stainback, S., Stainback, W., & Forest, M. (1989), Educating all students in the mainstream of regular education. Baltimore: Paul H. Brookes.
- Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. Journal of The Association for Persons with Severe Handicaps, 13 (1), 41-53.
- Turnbull, R., Ellis, J. W., Boggs, E. M., Brookes, P. O., & Biklen, D.P. (Eds.). (1981). Least restrictive alternatives: Principles and practices. Washington, DC: American Association on Mental Deficiency.
- Turnbull, A. P., & Turnbull, H. R. (1986). Families, professionals and exceptionality: A special partnership. Columbus, OH: Charles E. Merrill.
- Vandercook, T., York, J., & Forest, M., (1989). The McGill action planning system (MAPS): A strategy for building the vision. The Journal of The Association for Persons with Severe Handicaps, 14, 202-215.
- Wehman, P., Renzaglia, A., & Bates, P. (1985). Functional living skills for moderately and severely handicapped individuals. Austin, TX: PRO-Ed.

- White, K. R. (1984). An integrative review of early intervention. Logan: Utah State University, Early Intervention Research Institute.
- Wilcox, B., & Bellamy T. (1987). A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities. Baltimore: Paul H. Brookes.
- Wolfensberger, W. (1972). Normalization: The principle of normalization in human services. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1980). Research, empiricism and the principle of normalization. In R. Flynn & K. Nitsch (Eds.), Normalization, social integration and community services (pp. 117-132). Baltimore: University Park Press.
- Ziarnik, J. P., & Bernstein, G. S. (1988). Consulting to developmental disabilities service agencies. In, M. Powers (Ed.), Expanding systems of delivery for persons with developmental disabilities. Baltimore: Paul H. Brookes.

APPENDICES

APPENDIX A

PREFERENCE AND CHOICE QUESTIONNAIRE

What are _____'s major means of communication?

_____	Speech	_____	Gestures
_____	Signing	_____	Gestures/Vocalization
_____	Vocalization	_____	Communication Device
_____	Other (specify)	_____	

What are some ways that _____ expresses pleasure?

What are some ways that _____ expresses displeasure?

What are some of _____'s particular likes?

How do you know?

What are some of _____'s particular dislikes?

How do you know?

How does _____ generally indicate preference when given a choice between two or more activities, foods, objects, and so forth?

What kinds of choices does _____ characteristically have the opportunity to make?

On the average, how many times per day does _____ have the opportunity to make choices concerning where, when, and what to eat; where, when, and how to spend leisure time; when to get up and go to bed; what to wear; with whom to associate; how to spend money etc.?

Never 1-5 times 5-10 times 10-15 times 15+ times

When was the last time _____ had an opportunity to make a choice?

Who usually decides what clothes _____ wears each day?

_____ The person	_____ Person and staff
_____ Staff	_____ Other (specify)

Who usually decides what _____ will do at any given time of day

_____ The person	_____ Person and staff
_____ Staff	_____ Other (specify)

Who usually decides how _____ will spend an allowance or other money?

_____ The person	_____ Person and staff
_____ Staff	_____ Other (specify)

What was the last choice situation?

What home-management activities does _____ prefer to do or assist with?

___ Shopping	___ Shovelling	___ Drying dishes	___ Child care
___ Mending	___ Setting the table	___ Pet care	___ Emptying the
___ Cleaning	___ Gardening	___ Cooking	trash
___ Clearing the table	___ Dusting	___ Ironing	___ Mowing the lawn
___ Repairs	___ Washing dishes	___ Farm chores	
___ Sweeping	___ Child care	___ Other (specify)	_____

How does _____ prefer to spend leisure time at home?

How often does _____ participate in recreation and leisure activities in the community, such as movies, plays, shopping, dances, video arcades, bowling, concerts, eating out, sports events, and so forth?

Frequently Sometimes Seldom Never

What are some examples of the community-based recreation and leisure activities that _____ prefers?

How often does _____ participate in this activity?

Activity

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

What are _____'s special needs or preferences concerning

_____ positioning? _____

_____ diet? _____

_____ health _____

At what time of day does _____ usually prefer to be active and productive?

At what time of day does _____ usually prefer to rest and relax?

Consider the following items. Which response might be most appropriate for your son, daughter, or other relative?

1. In most cases, when opportunities rise to make choices, _____ prefers to:

make choices independently	make choices with minimal help from others
make choices with moderate help from others	leave the choice completely to someone else
2. In most cases, _____ prefers situations that offer:

unlimited choices	many choices
few choices	no choice
3. In most cases, _____ prefers lighting which are:

very warm	somewhat bright
dim	virtually dark
4. In most cases, _____ prefers temperatures which are:

very warm	somewhat warm
somewhat cool	very cool
5. _____ prefers environments where there is:

lots of variety in activity from day to day	a moderate degree of change in daily activity
a low degree of change in daily activity	no change in activity from day to day
6. Most of the time, _____ prefers to be:

alone	with one other person	with a small group	with a large group
-------	-----------------------	--------------------	--------------------
7. Most of the time, _____ prefers to be:

very active	moderately active	relaxed
-------------	-------------------	---------

8. Most of the time, _____ prefers to be:
- independent supervised dependent
9. Most of the time, _____ prefers to be:
- with age peers with older persons with younger persons
10. Most of the time, _____ prefers to be:
- the center of attention one of the crowd seen but not heard
11. Most of the time, _____ prefers to be in the company of
- persons of the same sex persons of the opposite sex a mixed group no preference
12. Most of the time, _____ prefers to be involved in
- fast paced activities moderately paced activities slow paced activities
13. Most of the time, _____ prefers to be engaged in
- highly repetitive activities moderately repetitive activities nonrepetitive activities
14. Most of the time, _____ prefers to be in environments where there is
- lots of action a moderate degree of action limited action
15. Most of the time, _____ prefers to be
- in highly competitive situations in moderately competitive situations in noncompetitive situations
16. Most of the time, _____ prefers to be
- in highly structured situations in moderately structured situations in loosely structured situations
17. Most of the time, _____ prefers to be
- in unfamiliar new surroundings in familiar surroundings

18. Most of the time, _____ prefers to be

in highly visually
stimulating
environments

in moderately visually
stimulating
environments

in visually
stimulating
environments

19. Most of the time, _____ prefers to be

in noisy
environments

in moderately noisy
environments

in quiet
environments

20. If you can think of any other particular preferences that _____ may have regarding everyday surrounding, environmental conditions, likes and dislikes, etc., please list them below.

Has _____ ever indicated a preference for a specific type of career? If yes, what?

Has _____ ever indicated plans for the future? If yes, what are they?

COMMUNITY INVENTORY

Client's Name: _____

Date of Inventory: _____

Compiled By: _____

Fill out four strengths/preferences in each area:

Domestic

1.

2.

3.

4.

Recreation/Leisure

1.

2.

3.

4.

Vocational

1.

2.

3.

4.

Community

1.

2.

3.

4.

List two possible job sites (in clients home community) from the above compiled list:

Domestic

1.

2.

Recreational/leisure

1.

2.

Vocational

1.

2.

Community

1.

2.

Document times visited to preferred sites:

1. Place _____
Date/Time of Day _____
Client's reaction (behaviour, verbal comments, non-verbal expressions, other relevant observations) _____

2. Place _____
Date/Time of Day _____
Client's reaction _____

4. Place _____
Date/Time of Day _____
Client's reaction _____

5. Place _____
Date/Time of Day _____
Client's reaction _____

6. Place _____
Date/Time of Day _____
Client's reaction _____

7. Place _____
Date/Time of Day _____
Client's reaction _____

8. Place _____
Date/Time of Day _____
Client's reaction _____

9. Place _____
Date/Time of Day _____
Client's reaction _____

10. Place _____
Date/Time of Day _____
Client's reaction _____

APPENDIX B

PARTICIPATION MODEL OF ASSESSMENT

PHASE I: ECOLOGICAL INVENTORY STRATEGY / DISCREPANCY ANALYSIS

STEP 1 - ACTIVITY INVENTORY

STEP 2 - NORMAL PEER PARTICIPATION INVENTORY OR PATTERNS

STEP 3 - STUDENT INVENTORY OR PARTICIPATION EFFECTIVENESS

SUMMARIZE ON PARTICIPATION INVENTORY SHEET

PHASE II: ASSESS BARRIERS TO PARTICIPATION

STEP 1 - OPPORTUNITY BARRIERS

- 1) Discrimination Factors
- 2) Knowledge Barriers

STEP 2 - ACCESS BARRIERS

- 1) Mobility
- 2) Manipulation
- 3) Sensory Skills
- 4) Cognitive/Linguistic Skills
- 5) Augmentative Communication Profile
 - Student Profile
 - Vocabulary Development
 - Communicative Functions of Behaviour
 - Communication Interaction
 - Initial Vocabulary Selection

STEP 3 - ASSESS POTENTIAL INTERVENTION OPTIONS

- 1.) Potential to Utilize Adaptations
 - a.) Adaptation Requirement
 - b.) Adaptive Capability
 - c.) Constraints

STEP 4 - ASSESS POTENTIAL TO INCREASE NATURAL ABILITY

STEP 5 - ASSESS NATURAL SKILL PROFILE

STEP 6 - RE-ASSESS PARTICIPATION EFFECTIVENESS

Excerpted and adapted from Mirenda, P. & Iancono, T. (1990). Communication Options for Persons with Severe and Profound Disabilities: State of the Art and Future Directions. J.A.S.H. 15(1), 3-21 and the Augmentative Communication Profile, (1989) Harrisburg, PA: Pennsylvania Assistive Device Center.

PHASE I: ECOLOGICAL INVENTORY

STEP 1 - ACTIVITY INVENTORY

1. What activities is the student involved in? (what do they need to communicate about?)

STEP 2 - NORMAL PEER PARTICIPATION INVENTORY

2. How do typical kids communicate and what do they communicate about during those same activities? (Outline steps on Participation Inventory)

STEP 3 - STUDENT PARTICIPATION EFFECTIVENESS

3. How does the student's performance in the common activities compare to that of the typical student? (*Summarize performance on Participation Inventory*)
What adaptation might he/she require?
What means does she/he use already that could be strengthened?

PARTICIPATION INVENTORY

Student: _____

Domain: _____

Environment: _____

Subenvironment: _____

Activity : _____

Date: _____

STEPS IN PEER PARTICIPATION INVENTORY

STUDENT PERFORMANCE

ADAPTATIONS

[illegible]

2. Knowledge Barriers

- a. What opportunities does the student have for choice-making or self-initiated interactions?
- b. What communication system is the student required to use? ("eg. Would she/he be required to say it in a full sentence?)"
- c. What are some of the student's different nonverbal communicative behaviours (eg.gestures, idiosyncratic signs, aberrant behaviour) that you understand?
- d. Does the student seem to require a long pause time before he/she responds?

AUGMENTATIVE COMMUNICATION PROFILE

STUDENT PROFILE

1. **How does the student communicate most often?**
 1. Facial expressions
 2. Pointing/gestures/signs
 3. Reliable yes/no
 4. Vocalizations/verbal approximations or only written/typed/printed communication that is not always understandable
 5. Speech or written/typed/printed communication (uses one consistently)
 6. Speech ± written/typed/printed communication (uses both consistently)
 7. Other _____

2. **At what level does the student demonstrate reading abilities?**
 1. Below readiness
 2. Prereading/sight words
 3. First or second grade level
 4. Third or fourth grade level
 5. Fifth, sixth or seventh
 6. Above seventh grade

3. **Does the student have any previous experience with any symbol systems?**
 1. None
 2. Photos only
 3. Rebus/Picsyms/PCS etc (black & white line drawings)
 4. Blissymbolics
 5. Spelling/writing
 6. Icons/Minspeak or Lolec/Epson

4. **Has the student had any experience with augmentative communication?**
 1. None
 2. Only experimentally or only in therapy
 3. Uses one or more different types but used none outside of therapy
 4. Uses a system outside of therapy less than 50% of the time
 5. Uses a system outside of therapy more than 50% of the time
 6. Uses a system to communicate with speech output and one to produce written/printed/typed messages more than 50% of the time

5. **What is the student's present symbol system?**
 1. Photographs
 2. Pictures
 3. Black and white line drawings
 4. Blissymbolics
 5. Spelling, written words, phrases
 6. Icons or symbols with more than one meaning

6. **How many symbols, sounds, letter codes, or words does the student now use to communicate?**
 1. Less than 5
 2. 6 - 15
 3. 16 - 50
 4. More than 50
 5. More than 100
 6. Uses same symbols in more than one way
7. **How many symbols, letters, or words does the student use in sequence?**
 1. At present not using any in sequence
 2. Just beginning to learn sequencing
 3. Using sequencing of 2 symbols, letter codes or words
 4. Using sequencing of 3 symbols, letter codes or words
 5. Using sequencing of 4 symbols, letter codes or words
 6. Uses at least 5 different, two symbol or more sequences spontaneously
8. **What is the student's present structure of language?**
 1. Utterances and sounds only
 2. One word responses
 3. Simple, active, declarative phrases, sentences
 4. More complex but with omissions and some word order difficulty
 5. Includes all structural elements
 6. Shows mature patterns that are more complex and includes clauses
9. **What is the highest level of parts of speech presently used by the student?**
 1. Simple nouns or verbs
 2. Simple nouns plus verbs
 3. Adjectives and prepositions
 4. Articles and pronouns
 5. Verbs with endings: -s, -ing, -ed, irregulars
 6. Conjunctions and complex clauses
10. **What is the student's present and usual length of response?**
 1. Nonverbal
 2. Verbal approximations or written/taped/printed but not understood
 3. Speech or written/taped/printed response of single words
 4. Speech or written/taped/printed response of more than 3 words
 5. Speech or written/taped/printed response of more than 5 words
 6. Speech or written/taped/printed response of more than 7 words

- 11. What is the student's present rate of learning new symbols?**
 1. Has no symbol set
 2. 1 per month
 3. Less than 5 per month
 4. Approximately 5-10 per month
 5. More than 3 per week
 6. Very rapid, daily
- 12. For how many environments does the student have existing vocabulary units?**
 1. Communication environments not identified
 2. Has vocabulary for 1 environment
 3. Has vocabulary for 2 environments
 4. Has vocabulary for 5 environments
 5. Has vocabulary for more than 5 environments
- 13. Does the student demonstrate any written or printed communication?**
 1. None
 2. Scribbles
 3. Attempts, but not legible
 4. Legible written/printed or typed words
 5. Legible written/printed or typed sentences
 6. Legible written/printed or typed paragraphs of 3 or more sentences
- 14. What is the student's present spelling ability?**
 1. None
 2. Child recognizes some of the alphabet
 3. Child recognizes some sight words
 4. Spelling abilities of the 1st to 2nd grade
 5. Spelling abilities above the 5th grade
- 15. What is the student's present pointing/selecting response?**
 1. Needs to be trained
 2. Points or selects upon request "show me", "touch", "find", the (symbol)
 3. Points or selects on imitation
 4. Points or selects in response to question
 5. Points or selects symbol set spontaneously to request an item
 6. Points or selects symbol set to spontaneously comment
 7. Points or selects symbol set to carry on a conversation
- 16. What level of motivation to communicate is demonstrated by he student?**
 1. No apparent desire
 2. Inconsistent, less than 25% of the time
 3. Desire apparent 25% of the time
 4. Desire apparent 50% of the time
 5. Desire apparent 75% of the time
 6. Desire apparent 90% of the time

- 17. How much frustration does the student appear to experience when trying to communicate with his/her current communication technique?**
1. Almost always
 2. Frustration 75% of the time
 3. Frustration 50% of the time
 4. Frustration 25% of the time
 5. Frustration less than 25% of the time
 6. Almost never
- 18. How much of the student's present communication would someone unfamiliar to the student understand?**
1. None
 2. Less than 25%
 3. Less than 50%
 4. 50%
 5. More than 50%
 6. Almost all or at least 90%
- 19. To what degree does the student demonstrate understanding of the operation of his/her current communication technique?**
1. Does not seem interested in the system at this time
 2. Turns on system, attends to display of symbols
 3. Finds proper vocabulary selection
 4. Learns location of individual items
 5. Uses system to communicate
 6. Demonstrates increased speed in operation
- 20. How many different possible communication environments is the student in one week?**
1. Less than 2
 2. More than 3
 3. More than 5
 4. More than 8
 5. More than 10
 6. More than 15
- 21. How does the current communication technique appear to meet the student's needs?**
1. Does not meet needs
 2. Meets very basic needs without speech or printed/typed/written output
 3. Speech output for only basic needs
 4. Printed/typed/written output only for basic needs
 5. Speech and printed/typed/written output for basic needs
 6. Speech and printed/typed/written output for basic needs and desires

22. **How restricting is the current communication technique to the student? (size, shape, portability, power source...)**
1. Restricting in all situations
 2. In most situations
 3. In many situations
 4. In a few situations
 5. In a very few situations
 6. Presents no real problem in most situations
23. **Does the student's current communication technique appear to provide the student with any satisfaction or enjoyment?**
1. No noticeable satisfaction
 2. Very minimal because student is not always understood
 3. Minimal because system is very limited
 4. Some, but not necessarily communicating for the sake of enjoyment
 5. Beginning development of enjoyment and pleasure from communicating
 6. Satisfaction and enjoyment most of the time
24. **How does the current communication technique provide for telephone conversations, letter writing, note taking, games and entertainment?**
1. Has none
 2. Someone else speaks on phone or writes messages for student
 3. Student uses system for speech output or to type/print/write own message
 4. System produces speech and printed/written/taped messages
 5. System has speech, printer, quick note taking and computer access
 6. All of #5 and can be independently accessed by student

VOCABULARY DEVELOPMENT

Does the student communicate about the topics listed below? If so, please give examples of the means she or he uses to get the message across.

TOPIC	YES	NO	COMMUNICATIVE BEHAVIOURS
address			
boy/girl friend			
clothes			
comfort			
dresssing			
friends			
games			
home activities			
jokes			
medical needs			
music			
name			
pets			
recreation			
relatives			
school			
siblings			
special interest			
sports			
teacher			
thanks			
toilet			
travel			
television			
work chores			

COMMUNICATIVE FUNCTIONS OF BEHAVIOUR

COMMUNICATION INTERACTION

1. **Does the student initiate communication interactions?**
 1. 0%, never
 2. 10%, seldom
 3. 25%, occasionally
 4. 50%, frequently
 5. 75%, almost always
 6. 90%, every chance he/she gets

2. **How often does the student usually respond to communication interactions?**
 1. 0%, never
 2. 10%, seldom
 3. 25%, occasionally
 4. 50%, frequently
 5. 75%, almost always
 6. 90%, every chance he/she gets

3. **How do you usually understand the student?**
 1. Read the student's actions or behaviours to understand
 2. Ask the student yes/no questions to clarify
 3. Listen to or read student's verbal or written approximations and then ask questions to clarify
 4. Read student's communication board symbols or written messages and then ask questions to clarify
 5. Listen to student's output and check display or printed message and then ask questions to clarify

4. **How much of the student's communication is understood by peers?**
 1. 0%, peers don't seem to communicate with him/her
 2. < 20%, peers can' read symbols or messages and there is no speech output
 3. 20% - 50%, most of the time
 4. 50 - 75%, most of the time
 5. 75% - 90%, most of the time
 6. >90%, most of the time

5. **How often do peers & friends attempt to communicate with the student?**
 1. 0%, never
 2. 10%, seldom
 3. 25%, occasionally
 4. 50%, frequently
 5. 75%, almost always
 6. 90%, many times throughout the day

6. **How many persons appear to have successful communication interactions with the student each day?**
1. 0 - 2
 2. 3 - 4
 3. 5 - 8
 4. 9 - 14
 5. 15 - 20

INITIAL VOCABULARY SELECTION

IMPORTANT DIMENSIONS OF INITIAL VOCABULARY

	YES	NO
Frequently Used	_____	_____
Individualized	_____	_____
Reinforcing	_____	_____
Relevant to user	_____	_____
Flexible (generic)	_____	_____
Functions Included		
Requesting	_____	_____
Rejecting/refusing	_____	_____
Affection	_____	_____
Humour	_____	_____
Commenting	_____	_____
Greeting	_____	_____
Yes/No answers	_____	_____
Attention Gaining	_____	_____
Expressing State or Emotion	_____	_____
Topics Included		
Friends	_____	_____
Clothes	_____	_____
School Activities	_____	_____
Sports	_____	_____
Jokes	_____	_____
Music	_____	_____
Thanks	_____	_____
Travel	_____	_____
Special Interests	_____	_____
Comfort/discomfort	_____	_____
Toileting	_____	_____

STEP 3 - ASSESS POTENTIAL INTERVENTION OPTIONS**1.) Potential to Utilize Adaptations**

What should the symbol set look like?

Size?

Location?

Number?

Vocabulary? Check "Activity Inventory" and "Important Dimensions of Initial Vocabulary".

B.) Adaptive Capability

What prompting strategies are required?

What mode is best for receptive understanding?

C.) Constraints

Are there financial constraints?

Are there family or client constraints?

Are there opportunity constraints?

Decisions regarding Adaptation Options

STEP 4 - ASSESS POTENTIAL TO INCREASE NATURAL ABILITY

STEP 5 - ASSESS NATURAL SKILL PROFILE

DECISIONS REGARDING "TOMORROW SYSTEM"

APPENDIX C

Data Collection Protocol:
The Resident Lifestyle Inventory

Arranging for the Interview

Review the data collection procedures listed in this document. Then call the residential program you will be visiting, at least two weeks in advance, to arrange for the visit. Speak with the director of the program and arrange a date and time when the necessary participants can be interviewed. Two days before you travel to the site, call again and remind the director that you will be coming.

Participants

The interviewer will ensure that at least two persons (anchors) will be attending and participating in the interview along with the resident. These can be staff members, parents, guardians, etc. who have day-to-day knowledge of the resident's activities. One of these persons should have either lived with or been in daily contact with the resident for at least the six-month period preceding the interview.

The two individuals attending the interview with the resident provide information only when:

1. The resident does not respond to the question within 5 seconds, or;
2. One of the two anchors perceives the information reported by the resident to be incorrect. In these cases both anchors must reach a consensus on all data they furnish on behalf of the resident (for example, if they are listing the activities that a resident is involved in they must both agree on the type of activity, the number of times it occurred, and whether it most often happened in the home or community).

Data Collection

On your first visit with the resident begin the interview by telling the individual that the information for the interview will be used to support a research study. Next tell the person the risks associated with participating in the study (e.g., the interview form could be stolen from a locked file at the university or it could be inadvertently lost). Then, inform them that: a) they do not have to participate in the study unless they choose to and that there will be no repercussions for choosing not to participate; and b) they can also call up at any time and ask that their information be removed from the study and destroyed. Let them also know that if they are tired during the course of the interview they can opt to have the anchors finish answering the questions for them. After sharing this information with them then ask him/her if they are willing to participate in the study. If the answer is yes, then proceed with the interview. (After the initial contact has been made and consent has been received you

need only ask the residents if they are willing to continue as participants in the study). If the residents indicate that they are not willing to participate in the study, thank them for their time and terminate the visit at that point.

Interview Script

I'd like to ask you some questions about the things (activities) you have been doing around the house and in the community. I'm going to not only ask about the things you've been doing but also how often you perform the activity and whether you do the activity on your own or if the staff help you perform the activity. (The interviewer should proceed to ask the participants the following questions for each activity on the RLI. If an activity was not performed at least once in the last thirty days, do not try to gather information about the level of support required, or home vs. community location).

1. Activity frequency: About how often did the resident perform the activity in the last thirty days? For example, if they watched T.V. everyday the activity occurred 30 times.
2. Level of assistance: What level of assistance (if any) did the resident need to perform the activity?
 - A. "No Support"? (i.e., the resident performed the entire activity without assistance. This would include travel, if the activity happened in the community).
 - B. "Minimal Support"? (i.e., staff provided 2-3 prompts, checked on the resident at the end of the activity, or assisted the resident to perform a difficult step of the activity).
 - C. "More Than Minimal Support"? (i.e., staff remained in the same area as the resident and frequently checked on his/her performance of the activity, or staff provided frequent assistance).
 - D. "Substantial Support"? (i.e. staff provided repeated physical assistance, prompts, and/or constant supervision while resident performed the activity).

Most Frequent Location of the Activity

Where was the activity most often performed, in the home or community

APPENDIX D

DATA COLLECTION PROTOCOL SOCIAL NETWORK ANALYSIS FORM (SNAF)

Purpose of Form

This form provides information about a target individual's social network. It is used to identify (a) the names of social network members, (b) the "structure" of the social network (i.e., which network members are family, which are friends, etc.), c) the frequency with which the target individual does activities with each social network member, (d) the "importance" of each social network member, and (e) how long the target individual has known each social network member. The form may be used to obtain information about the social networks of anyone, but the protocol was specifically designed for conducting interviews with people who have severe developmental disabilities, who may find it difficult to answer some of the interview questions.

How the SNAF is used

The SNAF is used in a face-to-face interview. The interviewer asks questions and fills out the form. The target individual (i.e., the person with developmental disabilities) answers the questions directly, or receives assistance in answering the questions from two other participants (called "anchors"). The two anchors must be people who (a) have had day-to-day contact with the person being interviewed, (b) have lived with or provided support to the target individual for at least the six-month period immediately preceding the interview, and (c) claim to have intimate knowledge of the target individual's social interactions. Do not conduct an interview unless these criteria are met. Two anchors must be present at the time of the interview. The anchors serve three purposes:

1. The anchors "translate" the questions for the target individual. When an interview question is asked, the anchors should be encouraged to rephrase the question in any manner that they believe will facilitate understanding by the person with disabilities.
2. The anchors confirm the accuracy of responses. If the target individual provides information that the anchors consider to be incorrect, the anchors provide alternative information. Otherwise the anchors simply confirm the responses made by the target individual. The interviewer should record information on the SNAF only when at least two of the three interviewees are in agreement about an answer.
3. The anchors supply information directly. When the target individual does not respond to an interview question, or has difficulty responding to a question, the anchors may supply the answers directly. In some cases, the concepts associated with the SNAF will be difficult for the target individual. In these cases the two anchors are asked to provide their best answer to the interview question.

Data Collection Procedure

Step 1: Clarify purpose of interview:

(Begin each interview by reading the following paragraph, which explains the purpose of the SNAF and the manner in which the information will be used).

"The SNAF is an interview form used to collect information about the social networks of people. a social network is the group of people you do activities with, or people who are important to you. Social network members are usually people who also provide you with what is called "social support". Some typical kinds of social support are (a) information on day-to-day events, (b) feedback on the appropriateness of behaviour, (c) help in making decisions, (d) emotional support at times of stress or celebration, (e) material aid and services, (f) access to other people, and (g) companionship. I am interested in learning about social networks so that we can learn how to better assist people to build and maintain the kinds of social networks that they want. The interview will take about 20-40 minutes".

Step 2: Clarify consent:

(If the target individual is part of a research project, ensure that an approved informed consent form has been signed by the target individual [or his/her designee]. Read the following paragraph to clarify consent).

"Your answers to the questions I'm going to ask are voluntary. You may decide to withdraw from the interview at any time for any reason without any problems".

Step 3: Clarify role of anchors:

(Review with the anchors the purpose of their participation by reading the following paragraphs).

"Thanks for agreeing to serve as 'anchors' in this interview. As an anchor you serve three purposes:

You 'translate' the questions for the target individual. When I ask an interview question, you should feel free to rephrase the question in any manner that you think will help make the meaning clearer.

You confirm the accuracy of responses. If the target individual provides information that you think is incorrect, you should provide alternative information. My job is to record information on the form only when at least two of you interviewees are in agreement about an answer.

You supply information directly. When the target individual does not respond to an interview question, or has difficulty responding to a question, you should supply the answers directly. Simply provide the best answer that the two of you can agree upon".

Step 4: Complete demographic information at the top of the form:

(Complete the demographic information at the top of the form by filling in all the blanks).

Step 5: Read the script for listing social network members and activity frequency:

"Now I would like to find out the names of your social network members. To make this easier, I'll group the people into categories. I'll name a category of social networks members, such as 'Family', and you tell me the names of all the people in that category who have done at least one activity with you in the last 30 days. Let's start with members of your family. Tell me the names of all family members who have done at least one activity with you in the last 30 days".

(List the names of family members on the form until the target individual and the anchors stop identifying people [i.e., until there is a five to ten second pause]. Then say,

"Are there any more people in this category or should we move onto another category?"

(Continue to list additional names in a category, if they are provided, until another five to ten second pause occurs. Then move on to the next category. If the person being interviewed remembers the name of a network member in a category that you have already completed [e.g., remembers a "friend" when you have already moved to the "Neighbours/Others" category], add the new person(s) to the appropriate category). Also, if more than 10 people are listed in any category, use the "Additional Network Members" space at the end of the form. List the category and the additional people in this space. Note that people from more than one category may be listed in the "Additional Network Members" space [e.g., Family: Uncle Fred; Friend: Sam Smith]).

"Now that we have a list of your social network members, I'd like to find out some additional information about your relationships with them. First I'd like to know approximately how many activities you've done with your social network members in the last 30 days. Let's start with family. I'll read the names and, for each family member, you tell me approximately how many activities you did with that person in the last 30 days".

(Read the names aloud and write down the number of activities. Do this for each of the social network categories)

Step 6: Read script for determining importance of social network members and duration of relationship:

"Now that I have information about social network members and how often you've done activities with them in the last 30 days, I'd like to find out which of your network members are socially important to you, and how long you have to know each of them.

People who are socially important to you are usually those people with whom you like to spend time, or people who do important things for you. Socially important people may provide you with social support, such as: (a) information of day-to-day events, (b) feedback on the appropriateness of behaviour, (c) help in making decisions, (d) emotional support at times of stress or celebration, (e) material aid and services, (f) access to other people, or (g) companionship. In considering whether someone is socially important to you, you may want to ask yourself, 'Do I like spending time with this person?' or 'Is the type and amount of social support that this person provides me with important?'

Let's start with the family members in your social network. I'll read each name aloud, and you let me know if that person is socially important to you. You can simply answer 'yes' or 'no'. Then tell me how long you have known that person, even if he or she is someone who is not important to you".

(Read the names in the category. Put a check mark in the "importance" column if the person is important, otherwise do not make mark in the column. Do not go on to the next category until you completed step 7, which is scripted below).

Step 7: Read script for listing additional social network members

(On occasion a target individual's social network will include people who are important, but who have not done an activity with the individual in the last 30 days. It is important to list the names of these social network members too. Here is the script for gathering the names of these network members).

"Before we move on to the next category I'd like to know the names of any other family members who are important to you, but who did not do any activities with you in the last 30 days. Let me read the list of people in this category so far. (Read the list of people in the family category). Can you think of any other people who are important to you, but who you did not do any activities with in the last 30 days?"

(List the names of additional people in that category until the target individual and the anchors stop identifying people [i.e., until there is a five to ten second pause]. Then say,

"Are there any more people in this category or should we move on to another category?"

(Continue to list additional names, if they are provided, until another five to ten second pause occurs. Record a zero in the column that notes the number of activities that the target individual has done with these people, and put a check mark in the "importance" column.

"Finally, before we move to another category, I'd like to know how long you have known each of the social network members in this category". (Note that this column is not completed for the "family" category).

(Repeat steps six and seven for the remaining categories).

Step 8: Identify information source and confidence level:

(Note on the SNAF whether the information on the form was generated (1) entirely by the target person; (2) mostly by the target person; (3) with about equal contribution from the target person and the anchors; (4) mostly by the anchors; or (5) entirely by the anchors. Next, read the following script unless the target individual provided all or most of the information (i.e., unless you circled a "1" or a "2" on the form).

"Now, I'd like to ask you anchors how confident you are in the answers you provided. On a scale of 1 to 10, with 1 being "not very confident", and 10 being "very confident", (show them the Likert scale), how confident are you, in general, about the answers you provided?"

(Circle the answer the anchors provide).

Termination of the Interview

(Terminate the interview by thanking the participants for their time and candor. Be sure to ask if they have any questions about the process, or if they have any additional information that would help you understand the social network of the target individual).

SOCIAL NETWORK ANALYSIS INTERVIEW FORM

Person Interviewed: _____
 Date of Birth: _____ Sex: _____
 Disability: _____
 Anchors Interviewed: _____

Date: _____
 Interviewer: _____
 Program: _____

"In the following categories, name all the people with whom you have done at least one activities in the last 30 days"	"Approximately how many activities have you done with this person in the last 30 days?"	"Do you consider this person to be socially important? People who are socially important typically are those people who provide and/or receive: (a) information on day-to-day events, (b) feedback on appropriateness of behaviour, (c) help with making decisions, (d) emotional support at times of stress or celebration, (e) material aid and services, (f) access to other people, (g) companionship, etc."	"How long have you known this person?"
FAMILY			
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
CO-WORKERS/SCHOOLMATES/CO-RESIDENTS			
11.			
12.			
13.			
14.			
15.			
16.			
17.			
18.			
19.			
20.			

APPENDIX E

SCORE CODE: 0 = No evidence of this quality indicator

1 = Some evidence of this quality indicator (because it occurs sometimes though not consistently; because a "successive approximation" occurs or because it occurs for some but not all students or staff)

2 = The quality indicator is clearly evident for all students/staff

1. PROGRAM PHILOSOPHY (cont.)

	Score	Comments
13. An educative approach and "least intrusive means" guidelines are followed to intervene with behaviour problems.		
14. The program philosophy emphasizes integrated therapy rather than a pull-out direct service model.		
15. The program philosophy emphasizes continuous updating of services by actively seeking information on new curricular developments.		
16. The program philosophy supports the need for staff inservice training on a regular basis.		
17. The program philosophy emphasizes the continuous updating of services by actively seeking collegial interactions with experts in the field.		
18. The program philosophy emphasizes sharing its own innovative and effective efforts with other services in the region.		

2. PROGRAM DESIGN AND STUDENT OPPORTUNITIES FOR LEARNING

The major program design components and the social-environmental context for teaching and learning activities.

	Score	Comments
19. Students are given opportunities to make choices, provide input, and so forth, (e.g., asking a student where he or she would like to sit).		
20. There is evidence of longitudinal planning to prepare students for the demands of subsequent environments.		
21. Student transitions are facilitated by regular contact between "feeder" and "next" programs/schools (including community college and/or rehabilitation agency for secondary age).		
22. Students spend increasing amounts of time in the community for training as graduation approaches.		