

***Our Most Vulnerable Citizens:
Report of the Adult Task Force***

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Preface

This study grew out of the "Strategic Plan: OSAC Initiatives for 1990 and Beyond", and a decision by the Board of the Ontario Society for Autistic Citizens (now Autism Society Ontario) to create and sponsor a Task Force to examine the status of adults with autism and pervasive developmental disorders (PDD) resident in Ontario.

The purposes of the Task Force were:

- a) To identify the range of adult issues and their ramifications to adults with autism/PDD, parents, chapters, the provincial society, government, service providers, and outside organizations;*
- b) To initiate and monitor a plan which addresses the existing issues and prepares for future need;*
- c) To recommend funding initiatives which will ensure the continuity of established programs, their extension and expansion, and the development of new programs.*

The growing awareness by those in the field of the increasing number of children who now have diagnoses of autism or PDD and are in the process of becoming adults underlined the need for the Task Force. It also gave a sense of urgency to its work as it began meeting in 1990, first in Hamilton and later at the University of Guelph.

The format of the study is in line with the decisions of the Task Force taken early in its mandate. It was decided to undertake an extensive review of the literature on the needs of persons with autism and PDD and existing service models, and to create a survey to collect data on adults and older adolescents with autism/PDD with regard to their present status vis-a-vis a broad range of issues. Five case profiles were created to highlight and humanize the data.

This report that presents the results of the Task Force to date is not an end in itself. It aims to create a basis for further action by the Task Force directed to stimulating informed discussion and decision-making to meet the needs of adults with autism/PDD in the 1990s and beyond.

The Board of Directors of Autism Society Ontario gratefully acknowledges the work of the members of the Task Force named on a previous page. Special thanks are due to Dr Susan Bryson for designing the literature review and writing original essays on the needs and service models, Barbara Donaldson and Susan Day-Fragiadakis for preparing and targeting the data surveys, Elaine Williams for directing the data collection phase from the provincial office, and Victoria Bloomfield for the complex task of entering the data. Elizabeth Bloomfield compiled the statistical tables and edited and formatted the final report. Claire Zeijdel co-ordinated the case profiles, with contributions from Susan Bryson, Barb Donaldson and Elaine Williams. We thank other members of the Adult Task Force of Autism Society Ontario in 1990-1991: Kate McBrearty (Director of ASO), Marius Hoefman, Joseph Umbrico and Neil Walker.

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November 1991*

***Our Most Vulnerable Citizens:
Needs of, and Service Models for, People with Autism***

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*Requested by and submitted to the Autism Society Ontario
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September, 1991*

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Introduction

Health has been defined as a state of "physical, mental and social well-being, and not merely the absence of disease or infirmity" (World Health Organization, 1947, p. 793). This same view is expressed by the Premier's Council of Ontario (1989), who focus on the importance of empowering people "to realize their full health potential through a safe, nonviolent environment, adequate income, housing, food and education, and a valued role to play in family, work and the community". People with autism are among our most vulnerable citizens. For them a state of well-being depends on the co-ordinated efforts of several support services.

The Present Document: Intent and Scope

The intent here is to provide information relevant to the development and enhancement of community services for adolescents and adults with autism. The characteristics of the 802 adults identified in the Task Force's 1990 Ontario survey are summarized later in this book. The present document begins with a description of the syndrome(s) of autism. We then elaborate on the needs of people with autism, as dictated by current research findings and clinical expertise. This is followed by a discussion of existing models for serving people with autism and those with related disorders. Our main objective is to identify the ingredients deemed necessary to produce better outcomes for severely handicapped individuals. We end by making several recommendations, and by suggesting how future research might contribute to social policy aimed at enhancing the quality of life of people with autism and their families.

The Autistic Syndrome

Autism is considered the most severe developmental disorder. It begins at or near birth, and is marked by life-long disability. The syndrome is defined behaviourally, by a triad of impairments in social, communicative and thinking functions, and by the presence of repetitive or ritualistic behaviours (Denckla, 1986; Wing, 1981b, 1982). Most people with autism are also mentally retarded, although approximately 25 percent have near normal to normal (or above) measured intelligence (Bryson, Clark, & Smith, 1988; Lotter, 1966; Wing & Gould, 1979). Prognosis is generally poor (De Myer, et al., 1973; Lotter, 1974, 1978; Wolf & Goldberg, 1986). Despite their impairments, people with autism have a normal life expectancy, and virtually all require some degree of care or supervision throughout their lives. Accumulating evidence suggests that several neurological systems are impaired (Coleman & Gillberg, 1985), but the causes of autism remain to be identified. Thus, no specific medical treatment or prevention is currently possible.

The prevalence of autism has recently been estimated to be as high as 14-16 per 10,000, and boys are affected four times more often than girls (Bryson, et al., 1988; Sugiyama & Abe, 1989; Wing & Gould, 1979). The more inclusive diagnostic category of pervasive developmental disorder (PDD) encompasses individuals with autism and those with related disorders (APA, 1987). The latter include 1) children whose triad of impairments (social, communicative, and thought) is less severe than that required for a diagnosis of autism, most of whom are severely mentally retarded (Wing, 1981b; Wing & Gould, 1979), and 2) higher-functioning PDD children who often present initially with a complex, puzzling clinical picture, but whose deficits are strikingly "autistic" by early adolescence. Individuals in this second, more intelligent group may be diagnosed as having Asperger's syndrome (Wing, 1981a). The estimated frequency of the entire PDD category (autism and related disorders) is at least 22 per 10,000 (Wing & Gould, 1979). This yields a prevalence substantially higher than that reported

for Down syndrome (16/10,000; Bearn, 1979) or congenital deafness (10/10,000; Moores, 1979).

People with so-called classic autism look intelligent and are physically attractive as well (Wing & Attwood, 1987; Wing & Gould, 1979). However, they suffer a profound inability to relate either socially or emotionally. Their expressions of emotion are restricted largely to fear and anxiety. They also have extreme difficulty understanding emotional expressions in others (Hobson, 1986; MacDonald, et al., 1989). Social interactions are avoided and even physically rejected, and the youngsters do not seek or initiate human contact themselves (Kanner, 1943). Autistic withdrawal is particularly characteristic of, but not restricted to, social situations. People with autism are unresponsive to much of their environment. When left to their own devices, they fail to initiate nonsocial activities as well.

The striking exceptions are those few behaviours which people with autism perform in a rigid, ritualistic and repetitive manner. These range from simple motor stereotypes (e.g., rocking, flapping the arms, or flicking the fingers in peripheral vision) to systematic ordering of objects, or preoccupations with certain objects (e.g. fans, shiny paper) or themes (e.g., timetables). They also include the isolated abilities, typically involving number, music or reading, which often co-exist with good rote memory (Rimland, 1978). These repetitive behaviours predominate in the absence of more functional activities, and even the most remarkable of the isolated abilities are of limited use. Individuals with "exceptional" numerical abilities, for example, do not see their application in everyday life (e.g., cannot make change). Similarly, the ability of people with autism to read words far exceeds their understanding of what has been read (Cobrinik, 1974; Healy, et al., 1982).

One third to one half of people with autism have no speech (Bryson, et al., 1988; Lotter, 1966; Wing & Gould, 1979). Those who do speak are either noncommunicative, or ineffective and socially awkward

(Prizant & Schuler, 1987; Tager-Flusberg, 1981, 1986). Affected individuals have difficulty understanding the many nuances of language. Even more striking is their inability to use language for conversational purposes. When present, their language is characterized by unusual intonation and rhythm, and by a marked tendency to perseverate on a few topics. The communicative impairment is considered by many as the core and single most handicapping aspect of autism (e.g., Rutter, 1978b; Schopler & Olley, 1982).

The manifestation of autism depends on both the chronological and mental (intellectual) ages of those affected. It thus varies across individuals, and within the lifespan of any particular person. Many people with autism are (or have been) aloof, but some are socially passive, and others (generally the higher functioners) are socially active but distinctly odd (Wing & Attwood, 1987; Wing & Gould, 1979). With the onset of puberty or early adulthood, many become more socially aware. Even so, this occurs in the absence of acquiring even the most elementary skills required to meet their social needs (Kanner, Rodriguez, & Ashenden, 1972; Mesibov, 1983; Rutter, 1970, 1978a; Wing, 1983). Such awareness in the absence of skill no doubt contributes to the high incidence of psychiatric problems, notably, anxiety and/or depression, in adolescents and adults with autism (Gillberg, 1984; Rutter, 1970; Wing, 1983). Additional problems of adolescence include the development of epilepsy (25-30%, most of whom are also severely retarded; Lotter, 1966; Rutter & Lockyer, 1967), inappropriate sexual behaviour, and aggression which in physically mature people is difficult to manage (De Myer, et al., 1973; Mesibov, 1983). As many as 30 percent of people with autism show clear evidence of behavioural deterioration in adolescence, although in some this may be only transitory (Kanner, Rodriguez, & Ashenden, 1972; Gillberg, 1984).

In all affected individuals, autism is a life-long, pervasive disorder involving most (if not all) adaptive functions. Indeed, it is this aspect of the disorder - the failure to acquire functional behaviour - which

distinguishes people with autism most from other developmentally disabled groups (Jacobson & Ackerman, 1990), and which prevents them from functioning independently in society. The nonverbal, severely mentally retarded person with autism may repeatedly bang his/her head, or lash out and scream when frustrated. Much of his/her time is spent wandering aimlessly or engaged in such activities as spinning, shredding paper or staring at particular objects. Other individuals are less intellectually impaired, but they too have acquired few, if any, self-care or adaptive skills. They also adhere rigidly to certain routines, have extreme difficulty with any change, and are fundamentally impaired in relating to others. The so-called higher functioning people with autism (near normal to normal "intelligence") present with somewhat different, but no less challenging problems in adaptation. These more verbal individuals have virtually no sense of how to attain any goals, be they social, educational or vocational. Sustaining motivation is thus a problem, and both depression and anxiety are common. High functioning people with autism are socially awkward and inappropriate, their conversation is restricted to few (repetitive) topics, and they have significant difficulties using their knowledge in any practical way. Definitions of mental handicap which include level of adaptation as well as I.Q. (e.g. Grossman, 1983; ICD-9, 1980) place most people with autism in the lowest (most challenging) functional categories.

The Needs of Adolescents and Adults with Autism

For the present purposes, we focus on the needs considered central to effective planning for adolescents and adults with autism. These include 1) the need to communicate, 2) the need for structure, 3) the need to work and to participate in recreational and leisure activities, 4) the need for a safe and caring place of residence, and 5) other related needs. This section draws heavily on research findings, and on the experience of experts in the field of autism and related disorders. While

authors differ in their particular interests, agreement exists regarding the major needs of people with autism.

1. *The need to communicate.*

The need to communicate one's wants or desires, and more generally, to interact in a meaningful way with others, is viewed as a priority for all individuals with autism (e.g., Lord & O'Neill, 1983; Mesibov, 1983; Prizant & Schuler, 1987). As noted previously, the communication deficits associated with autism are distinct in three ways: 1) A substantial proportion (one third to one half) of people with autism have no speech; 2) Those with speech do not use language (or gestures) to communicate with others; and 3) People with autism do not appreciate even the most basic rules governing social interactions. The significance of the communication/social impairment is underscored by the difficulties integrating this population into community life. Indeed, the most frequently cited reason for unsuccessful placements of people with autism in residential or vocational settings is their poor (or inappropriate) communication and social skills (Henning & Dalrymple, 1986; Mesibov, 1983; Prizant & Schuler, 1987).

The major priority for any person with autism is to establish some (ideally the least restrictive) means of communicating. The importance of this is well illustrated in the story of Helen Keller, a congenitally deaf girl (Weiner, 1970). Among the several parallels between those who are deaf and those who are autistic is that the ability (and opportunity) to communicate is associated with a marked decrease in various problematic behaviours, including aggressive outbursts and extreme withdrawal (e.g., Casey, 1975; Wing, 1983). The availability of a method of communicating (either verbal or nonverbal) is also the first vital step in attaining any autonomy in the larger community.

Once established, the challenge is to ensure that people with autism use whatever communication skills are available to them. Affected individuals are either noncommunicative, or language is used

only to satisfy their basic needs (Prizant & Schuler, 1987; Tager-Flusberg, 1981). While the latter is important, integration into the larger community requires the development of socially appropriate communication skills. Thus, social communication training, conducted within the relevant residential, vocational and recreational settings, must be seen as a priority. The period of adolescence and adulthood is a critical time for such training, precisely because at this age many people with autism become interested in social interactions. They are thus more internally motivated to acquire the relevant communication skills (Mesibov, 1983; Rutter, 1970; Wing, 1983).

Research on autism indicates that if communication skills are to be functional, they must be taught in the natural settings in which they occur (Prizant & Schuler, 1987). Learning is typically a slow process, and should take place in a variety of contexts with different people, to ensure that what is learned generalizes across experience (Lovaas, et al., 1973). People with autism do not know what to say (or do) in different contexts. It is thus essential that communication training make explicit the rules governing appropriate social behaviour (Mesibov, 1983; Wing, 1983). These include such things as saying "hello" before starting a conversation, knocking on the door before entering someone's room, and asking for help when confused or lost. The development of such skills serves the dual purpose of increasing the probability of integration into the community, as well as meeting the affected individual's own need for social relationships outside the family (Lord, 1988).

2. *The need for structure.*

It is well established that people with autism fare best in highly structured, predictable and familiar surroundings (e.g., Fredericks, et al., 1983; Mesibov, 1983). Much of their behaviour, notably the rituals and attempts to order things, can be understood as a need to maintain sameness (Kanner, 1943). People with autism find all change extremely difficult. When confronted with new places or new people, minor

changes in routine, or the demand to learn something new, they typically experience severe and even incapacitating anxiety.

Individuals with autism benefit from structure in at least three important ways. First, structure facilitates their learning (Schopler, et al., 1971). Much of the world is confusing to people with autism (Hermelin & O'Connor, 1970), particularly that which is novel, complex or unpredictable (Hutt, et al., 1964; Dawson & Lewy, 1989). Structure affords some control over such events, thereby reducing anxiety and enhancing learning. Evidence indicates further that learning itself must be structured: the skills to be acquired must be taught systematically (e.g., broken down into their component parts), and that which is normally implicit (e.g., which behaviour is appropriate when) must be made explicit to maximize the usefulness of what is learned.

Structure also ensures some degree of activity. People with autism rarely initiate activities, not because of disinterest, but rather, because the thought simply fails to occur to them, or they have difficulty carrying out the necessary actions. In the absence of structure, they tend to withdraw, either doing nothing or engaging in repetitive, nonproductive behaviour (Paul, 1987). Extended periods of either are detrimental in several respects, not the least of which is the valuable time lost not doing something more useful or personally fulfilling.

The third and related way in which structure benefits people with autism is by reducing their frustration and physical aggression (Favell, 1983; Van Bourgondien & Mesibov, 1989). This is accomplished by preventing those environmental events associated with aggression, and by ensuring that affected individuals remain active, and that what is expected of them is both comprehensible and attainable. Inactivity, overwhelming confusion and repeated exposure to failure are all known to produce aggression (Dollard, et al., 1939). In structured settings, it is possible to introduce change gradually, while teaching people with autism the skills required for daily living.

One final comment is warranted. Structure in this context refers to attempts to be consistent, systematic and responsive to the uniqueness of each person with autism. The intent is not merely to control behaviour, but rather to monitor novelty, complexity and unpredictability, such that anxiety and frustration are minimized and the acquisition of adaptive behaviour is maximized. Some degree of structure may always be necessary, but its form must change as the person becomes more functionally independent. It must also be sufficiently flexible to allow people with autism to express and develop their own individuality and personal interests.

3. The need for work and recreational-leisure activities.

The need to work and to participate in recreational or leisure activities appears universal, in large part because such activities structure and give meaning to our existence (Herzberg, 1966). Work and recreation provide a vehicle by which people with autism can experience mental as well as physical well-being: they ensure some degree of activity, they are the bases of most social interactions, and they provide a sense of mastery and accomplishment, and of being valued by others. Work and recreation increase self-esteem by providing people with autism an opportunity to be productive and independent.

Empirical findings indicate that only 10-15 percent of people with autism are gainfully employed (Lotter, 1974, 1978; Wolf & Goldberg, 1986). The major problem by all reports is not one of acquiring the requisite job skills (Cunningham & Presnall, 1978; Fredericks, et al., 1983; Hayes, 1987; Rutter, 1978a). Rather, individuals with autism do not fare well in vocational settings because of 1) inadequate and/or inappropriate social behaviour, and 2) a poor work attitude, notably, little initiative and an inability to be flexible or to cope with changes in routine. Conversely, success in the workplace is associated with jobs characterized by regular routines, which do not require flexibility of thought or the ability to adjust to changing demands,

or much interaction with others, and which are supervised by patient, understanding people (Wing & Wing, 1976).

Research indicates further that access to either vocational or group home settings depends on the ability to occupy self during breaks, and to use free time appropriately (Van Bourgondien & Mesibov, 1989; Wing, 1983). These findings underscore the importance of acquiring recreational/leisure skills. Such activities are also associated with a reduction in abusive behaviour (Favell, 1983), and in the enhancement of social as well as physical skills (Wehman, 1983). The choice of work and recreational/leisure activities should depend on both the strengths and interests of each individual, and on more practical matters such as whether the relevant resources exist in his/her community (Henning & Dalrymple, 1986).

Work and recreational/leisure skills need to be taught systematically (e.g. sequentially, step-by-step), and people with autism need plenty of opportunity to practise and thus consolidate the new behaviours (Horst, et al., 1981; Wehman, 1983). Virtually everything has to be taught, including appropriate social and job-related behaviours. Some degree of monitoring may always be necessary, and substantial time and effort will be required initially to ensure that work and recreational/leisure skills are not only acquired but also used. Indeed, it is often necessary to structure the environment such that people with autism know when to engage in particular activities.

4. *The need for a safe and caring place of residence.*

Most (if not all) individuals with autism will require some care or supervision throughout their entire lives; many will require a great deal (De Myer, et al., 1973; Lotter, 1974, 1978; Wing, 1983). Residential settings other than the parents' home(s) are necessitated on several grounds. These include the severity of autism (and associated behaviour problems), the longevity of those affected, and the person's

own need with age to be more independent and self-sufficient. The families of individuals with autism experience a great deal of stress, even more than that documented for other chronic disorders (Holroyd & McArthur, 1976; Wolf, et al., 1989). The task of managing adolescents and adults with autism is clearly demanding, and aging parents find it increasingly difficult to cope, particularly in the absence of adequate community resources. Residential services are ultimately necessitated by the fact that most people with autism will long outlive their parents.

Research has only begun to address the important question of what kinds of residential programs are most suited to meeting the needs of adolescents and adults with autism. Preliminary evidence indicates that adaptation to group home living is more difficult for people with autism than other developmentally disabled groups (Van Bourgondien & Elgar, 1990). This is attributed to their profound deficits in social communication, the presence of perseverative and ritualistic behaviour, and their tendency to become agitated, self-injurious and aggressive. It also appears that generic residential programs are less structured and less well staffed than those specializing in autism, and that the staff do not have the knowledge necessary for effectively teaching people with autism. All of this no doubt contributes to the observation that the behaviour of individuals with autism is more problematic in generic than in specialized residential programs (Van Bourgondien & Elgar, 1990). Indeed, specialized services have developed world wide precisely because of the special needs of people with autism (e.g., extreme isolation and preoccupation, agitation/aggression or inactivity), and the time, effort and expertise required to develop their adaptive skills (see Special Issue on Residential Services, 1990).

Experts in the field of autism and related disorders (Schopler & Hennike, 1990; Zigler, Hodapp, & Edison, 1990) have recently argued for a continuum of residential services. Their main point is that no single service model will meet the varying needs of different disabled people. A continuum of services might include both generic and specialized

programs, and equally important, a continuum would provide various options for different people in different situations. People with autism differ markedly in their functional levels, in their family circumstances, and in the amount and type of care required to ensure their physical and mental well-being. Individuals with autism also differ in personal preferences. Such differences should be considered in all important life decisions.

5. Other related needs.

The need for advocacy and for adequate health services are related, but not central to our main purpose. Very briefly, existing medical services for people with autism are deficient in two notable respects. The first is the tendency to attribute all problematic behaviour to the syndrome of autism (Wing, 1983). Several psychiatric disorders, including anxiety, depression and psychotic symptomatology, occur with an increased frequency in adolescents and adults with autism (Gillberg, 1984; Wing, 1983). It is thus important to consider the person's total personality, and to be open to the possibility that additional problems may be influencing his/her behaviour. The second major deficiency in medical services is the failure to co-ordinate health care, which, among other things, may lead to unnecessary repetition of frightening and painful procedures (Dalldorf, 1983). Sensitive health professionals, who are aware of and interested in meeting the medical needs of people with autism, are best suited for this complex role.

People with autism need advocates to ensure that their rights and needs are not violated, and that existing services are appropriate and adequate for their well-being. This includes access to residential, vocational and recreational services which enable affected individuals to enjoy the least restrictive existence possible (Frolik, 1983; Geneva Centre, 1988). People entrusted with the important responsibility of advocate should be formally accountable to individuals with autism, to their families, and to all relevant agency personnel.

Summary

Autism and related pervasive developmental disorders occur early in life and are characterized by life-long disability. Affected individuals vary markedly in measured intelligence, although most score within the severely mentally retarded range. All people with autism suffer profound social and communicative deficits, and they engage in perseverative and ritualistic behaviour. Difficult to manage self-injurious and aggressive behaviours are also common. Adaptive functions are severely impaired, even in those with near normal or normal intelligence. Knowledge acquired is not useful in solving even the most basic problems in daily living. These, coupled with the presence of extreme anxiety and other psychiatric disorders, make adolescents and adults with autism a particularly challenging population. (Refer also to the 1990 Ontario survey of autistic adults which reflects these challenges.)

Priorities in servicing people with autism include addressing their social and communication needs, their need for structure and for work and recreation/leisure, and their need for a safe and caring place of residence. People with autism are both deserving and capable of fuller, more meaningful lives. Regressive behaviour decreases in frequency when they are more active and productive, when their anxiety is minimized, and when they are able to communicate. All of this is best achieved in highly structured learning and living environments. The acquisition of adaptive (functional) skills in people with autism also depends on staff having sufficient time, commitment and expertise. Some individuals with autism are capable of managing with relatively little supervision. Most will require substantial assistance to ensure any reasonable quality of life. Such diversity of need in different people in different family situations argues for a continuum of coordinated community services.

Models of Service

Until very recently, most people with autism were entirely segregated, and were housed in large institutions (Schopler & Hennicke, 1990). The focus was not on the development of life skills, nor was it assumed that these individuals would ever live in the community. As part of a larger social movement (Wolfensberger, 1972, 1975; Zigler, et al., 1990), the trend away from institutionalizing people with autism was precipitated by two factors: the development of expertise in teaching skills (and managing disruptive behaviour), and widespread concern about the quality of life of individuals with autism. Current attempts to integrate this population into the community have had dramatic effects on the lives of those concerned. The major problem is that most people with autism are either denied community services, or such services are discontinued, on the grounds that neither sufficient staff nor expertise exists (e.g., Holmes, 1990; Lauries, 1985; Smith, 1990; Van Bourgondien & Elgar, 1990). Existing services are grossly overextended, and most people with autism are accurately judged as challenging ("hard to serve") individuals. People with autism thus remain among our most vulnerable and our most poorly served.

It is against this background that specialized services have developed, not only in Canada, but in most advanced countries (Schopler & Hennicke, 1990). Services specialized for the needs of people with autism developed first as demonstration projects. The results have been overwhelmingly positive: even those with severe impairments are capable of some independence, and of enjoying the recreational facilities available in the larger community. Some individuals with autism have maintained steady employment in the work force, and virtually all can be engaged in meaningful or purposeful work activity. Having demonstrated impressive results, these innovative programs have survived and continue to develop. They serve as models for what is both possible and desirable.

The intent in this section is to identify the features considered essential to producing better outcomes for people with autism. It bears emphasizing that very few affected individuals - notably high functioners with no significant behaviour problems - have been able to access generic services. And even in them, problematic behaviour is more common in generic programs, as they currently exist (Van Bourgondien & Elgar, 1990). Discussion therefore focuses on specialized community-based programs. We begin by describing several programs designed specifically for people with autism or related disorders. The list is not exhaustive, but rather represents various viable possibilities. Attention then turns to the features shared by these programs. The main purpose is to benefit from the extensive experience of those who have successfully integrated people with severe and pervasive disorders into community life. We end by making several recommendations for the development and enhancement of community services for this very needy population.

Division TEACCH, North Carolina.

Division TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) is a state-wide, university-based program, developed first in 1972 in North Carolina (Van Bourgondien & Elgar, 1990; Schopler & Olley, 1982; Wall, 1990). As part of the University (University of North Carolina, Chapel Hill), the program encompasses service, teaching and research. Direct services for adolescents and adults include diagnosis and assessment, crisis intervention, social skills groups, job coaching and model program development. The recently developed Carolina Living and Learning Center (CLLC) is an integrated residential, vocational and recreational training program for 30 adults, located on the University campus. The Center's program is geared to the needs of severely impaired individuals, and is based on an apprenticeship model (i.e., all staff as part of their job teach an autistic person that job).

In addition to direct services, TEACCH consults to families and to all state-wide programs serving people with autism or related disorders (Wall, 1990). Based on individualized assessments of needs, TEACCH staff attempt to secure services for older clients in established classrooms, day programs, vocational settings and group homes (10 of which are specialized for the needs of people with autism, and an additional four are planned). TEACCH staff then assist in the development of programs aimed at better serving this very challenging population. For example, staff are actively involved in facilitating competitive or supportive employment, through job coaching and on-going support services.

TEACCH also assumes an active role in the planning of facilities for those who remain in North Carolina's Murdoch Center, a large institution (Schopler & Hennike, 1990). Murdoch Center currently serves individuals with severe or profound impairments, all of whom are multiply handicapped (i.e., many are either blind or hearing impaired, 30 percent have seizure disorders, 35 percent are non-ambulatory, and many have severe behaviour and/or medical problems). Residents of Murdoch Center are to be placed in the community, and clearly will require a great deal of care and intervention. As community facilities are developed, Murdoch Center is projected to become more specialized, providing, for example, special geriatric services for mentally handicapped people with major medical problems, and specialized services for the dually-diagnosed, and for individuals with highly assaultive or self-injurious behaviour. Murdoch Center might also engage in outreach activities, such as staff training and consultation in their areas of expertise.

With the support of the North Carolina legislature, Division TEACCH is committed to the development of a continuum of services for people with severe and pervasive developmental disorders (Schopler & Hennike, 1990). Training of parents, professionals and paraprofessionals is an integral part of TEACCH, as is a widely-attended yearly conference on various aspects of autism. TEACCH is further

distinguished by a continuing commitment to evaluate the effectiveness of its services. The program has received national and international recognition, and has served as a model for the development of similar programs throughout the world.

Specialized Services in Britain.

In Great Britain, centres specialized for the needs of people with autism are administered by the National Autism Society and its parent Branches (Van Bourgondien & Elgar, 1990; Wing, 1983). There are 28 such centres at present, located throughout Great Britain, and more are planned. The centres range from small hostels and group homes to larger residential homes and communities, where the vocational, recreational and residential programs are integrated in one setting (the model for North Carolina's CLLC). Both the size and the numbers admitted to each of the different centres vary. Approximately 500 adults are currently being served, and the demand for similar services is great.

The residential centres offer people with autism a life with appropriate structure, as well as flexible and individualized schedules. Within the continuum of services, a variety of occupations, models for self-care and recreational activities are provided. Most of the centres admit a proportion of very "hard to serve" individuals, but due consideration is given to the importance of maintaining a workable balance. The National Autism Society in England is working together with relevant authorities and other volunteer organizations to generate solutions for the sizeable group of severely and multiply handicapped adults.

Day programs are also offered through Great Britain's Social Education Day Centres and associated Special Needs Units. The latter have higher staff levels, and include ready access to necessary back-up services such as those provided by psychologists, language pathologists and occupational therapists. Special Needs Units provide a less

distracting environment for more severely impaired adolescents and adults who require highly individualized programs.

Kerry's Place, Ontario.

Kerry's Place was first developed in 1974, and continues to be the major community-based service for people with autism residing in Ontario (Mack, Konstantareas, & Finlayson, 1980; also see the newly developed St. Francis House, Sarnia, and Woodview Manor, Hamilton). Kerry's Place is administered by a Board of Directors (parents, Directors of the various Kerry's Place centres, and interested professionals), and is supported by the provincial Ministry of Community and Social Services. The continuum of services provided by Kerry's Place includes 6 group homes (both urban and rural settings), supported apartment living, job coaching and supported employment, respite service, and consultation to other programs serving people with autism or related disorders. Residents in Kerry's Place centres have the option of more sheltered work settings (e.g., a self-contained laundromat, or mobile work crews), as well as supported or competitive employment in the work force. Like TEACCH and the specialized centres in Britain, Kerry's Place provides for the individualized needs of adolescents and adults at different functional levels. Adequate staffing allows clients to achieve progressively greater independence in self-care and in vocational and recreational opportunities.

Kerry's Place is distinguished by its comprehensive in-service training of staff and active consultation with various professionals (e.g., language pathologist, experts in behavioural management). Kerry's Place also plays an active role in provincial and national conferences on autism. Its programs reflect current advancements in the education of adolescents and adults with autism, and the progress of individual clients is carefully monitored. The cumulative waiting list for Kerry's Place services exceeds one hundred.

Related Model Programs.

Other model programs include the Eden Family of Programs (New Jersey), Benhaven's Residential Program (Connecticut) and Bittersweet Farms (Ohio). All were first developed approximately 20 years ago, and have changed considerably in attempting to better serve the needs of larger numbers of people with autism or related disorders (Holmes, 1990; Kay, 1990; Simonson, Simonson, & Volkmar, 1990). Each program provides intensive residential and full-day programs aimed at fostering the development of independence and quality of life in the least restrictive environment possible. The programs are designed specifically to meet the communication and social-emotional needs of people with autism, as well as their need to engage in meaningful work and recreational/leisure activities. The focus is on education rather than simply caring for this "hard to serve" population. The programs encompass state-of-the-art methods in teaching and managing the problematic behaviours of adolescents and adults who are severely and pervasively impaired.

Several additional features distinguishing these programs deserve mention. The Eden Family of Programs offers, among other things, an innovative summer residential camp for both handicapped and non-handicapped individuals (Holmes, 1990). The camp serves many important purposes, including the much needed respite for parents. Benhaven draws heavily on the expertise of professionals from the Child Study Center at Yale University, including physicians with a particular interest in the well-being of severely and multiply impaired individuals (Simonson, et al., 1990). To ensure that residents are further integrated into the community (e.g., with smaller, more mixed groupings), Benhaven has developed a comprehensive community-based curriculum strategy in collaboration with various consultants (see Falvey, Gernot-Scheyer, & Luddy, 1987). Bittersweet Farms is an integrated (residential, vocational and recreational) farm setting modelled on that in England (Kay, 1990). It includes an active farm and life skills day program for nonresidents from the larger community (living with their

parents, in other group homes, or in local mental hospitals or developmental centres). Bittersweet Farms also offers an alternative education program, initiated by the local school district. This program serves multihandicapped adolescents whose placements elsewhere are unsuccessful.

Formal accountability is central to the integrity of each of these programs (e.g., Holmes, 1990; Kay, 1990). This includes accountability to the clients themselves, to their families, and to all relevant agencies. Careful attention is also paid to the working conditions of the staff, in an active attempt to maintain staff morale and to reduce staff turnover. Support for most of these programs comes from State Departments of Mental Retardation. In the case of Bittersweet Farms, recently designated as an Intermediate Care Facility for the Mentally Retarded, services are reimbursed by Medicaid. Each of the programs serves a substantial number of severely or profoundly impaired individuals, but considerable experience has shown that a mixture in the relative independence and dependence of clients is the best practice.

The Indiana Resource Center for Autism.

The Indiana Resource Center for Autism (IRCA) is part of Indiana University's Institute for the Study of Developmental Disorders (IRCA, 1990). It was established in 1985 in recognition of the urgent, compelling and special needs of individuals with autism. Very briefly, the Indiana 1979 General Assembly authorized an in-depth examination of existing services for people with autism and their families. A 1982 review of community-based programs indicated that this population was among the most "inadequately and inappropriately served". A 1984 needs assessment showed further that the involvement of service providers was measurably low, and that the preparation of professionals and paraprofessionals for serving people with autism was seriously inadequate.

Four pieces of legislation proposed by an ongoing Commission on Autism became law in Indiana in 1984 (IRCA, 1990). The first (Public Law 185) authorized the creation of the Indiana Resource Center for Autism (IRCA), as part of Indiana University's Institute for the Study of Developmental Disorders. The mandate is to centralize all data relevant to autism, to provide useful information, and to offer training and technical assistance to all service providers, students and families. Laws were also passed to prohibit exclusion of individuals with autism from community residential placements (Public Law 186), to provide a working definition of autism (Public Law 187), and to mandate an operational, inter-agency agreement regarding the provision of services to people with autism (Public Law 368). This agreement was co-ordinated by the IRCA, and in 1986 was signed by all leading agencies. House Bill 1195A, passed in 1987, requires IRCA to conduct regular needs assessments (one every three years) to determine the status of services to people with autism and their families. Thus Indiana's mandate to serve this population is accompanied by systematic attempts to ensure that adequate resources actually exist to effect any change.

The IRCA is committed to the goal of community integration for people with autism. This includes integration into community work sites, educational programs, recreation and leisure activities, and residential settings. The Center also focuses on the social and communication needs of these very challenging individuals. In addition to assisting parents to access services, an interdisciplinary team, experienced in model program development for people with autism, works directly with any state or community agency serving this population. The team trains professionals as well as paraprofessionals and families, and works from a consultation model designed to facilitate co-operative problem solving between all parties involved. As part of the University, the Center is committed to program evaluation/ research and to the dissemination of information about all aspects of autism.

The IRCA developed from expressed needs, and with legislation consistent with the goals stated in the 1983-1986 State Plan for Developmental Disabilities and the 1985 Update of that plan (IRCA, 1990). The Center encompasses training, information and research. Its purpose is to ensure that people with autism or related disorders enjoy as productive and independent lives as possible.

Community Services for Autistic Adults and Children, Maryland.

Community Services for Autistic Adults and Children (CSAAC), located in Rockville, Maryland, has developed innovative and highly successful programs for people with severe and pervasive handicaps (CSAAC, 1988; Smith, 1990; Warren & Juhrs, 1984). These include residential and vocational programs, and the Community School of Maryland. The residential programs, each of which serves a maximum of 3-4 clients, are situated in garden apartments, townhouses and single families throughout the state. The number of counsellors in any one unit depends on the needs of the residents (ranges from 1 per 40-hour week to 2 around the clock, 7 days a week). The counsellors live with the residents on a rotating basis, and are responsible for teaching relevant life skills (e.g., housekeeping, personal hygiene, money management, communication and leisure activities). All residents have a job/and or individualized full-day program.

The vocational program offers supervised employment and a wide range of job-related services (e.g., career planning, personal adjustment, travel and work training). The goal is to develop in every person with autism, the personal, social and work skills necessary for employment. Initial assessments include an evaluation of each client's abilities, needs and interests. An individualized program plan is then developed, and the client is placed in a work site under the tutelage of a CSAAC counsellor. CSAAC has several work training sites (printing, electronics, recycling and mailing operations), and new sites are continually being developed. The vocational program is distinguished by

its remarkable success in placing virtually all people with autism, even the more severely impaired, in supported paid employment.

The Community School in Maryland serves severely and profoundly handicapped adolescents with autism. Educational and vocational training, as well as related services (occupational therapy, communication expertise, and psychological consultation), are provided on a full-time basis. Students live with residential staff in a CSAAC Community home. A minimum ratio of one staff to two pupils is maintained at all times. The purpose is to prepare severely handicapped people to live and participate in the larger community. This is accomplished by individualized instruction in the many diverse skills required (e.g., functional academics, self-care, communication and socialization, and recreational and prevocational skills).

CSAAC exemplifies quality programming that fully integrates adolescents and adults with autism into the community. The focus is on teaching life skills, using positive (nonaversive) behavioural techniques to manage disruptive and inappropriate behaviour (Smith, 1990). Staff receive extensive pre-service and in-service training. CSAAC is accredited by the Accreditation Services for People with Developmental Disabilities, and has received several prestigious awards for its exemplary services to people with autism and their families (CSAAC, 1988). In 1984, CSAAC was designated a Model Program by, among others, the Office of Special Education and Rehabilitation, and was granted Federal funds to refine and disseminate its methods. Professional staff are actively involved in research, publish widely in recognized journals, and present regularly at regional and national conferences. Their research focuses on treatment techniques and integrated community services for people with autism and other severe handicaps. CSAAC convened the first 1986 Annual Symposium on Alternatives to Punishment in the Management of Severe Behaviour Disorders, and has co-convened several other national and regional conferences (together with local universities). The success of CSAAC's programs is well

documented, as is detailed information about the nature of their techniques (e.g., Smith, 1990).

In order to maintain the quality of its services, CSAAC has limited further growth and will instead serve as a model for, and provide technical support to, other programs and community agencies. The program is currently being replicated with Federal funds in four additional sites. CSAAC programs are supported primarily by the State Departments of Health and Mental Hygiene, and of Education. Additional support is provided through local governments and donations. CSAAC was first developed in 1979 by parents and professionals of the Maryland Society for Autistic Adults and Children. The Society was responding to the striking lack of services for a population at high risk for institutionalization.

Features Shared by Model Programs

Funding Concerns.

Programs designed for the needs of people with autism depend heavily on Provincial or State support. Some receive Federal funds as well, and some are "topped" with local government funds and/or private donations. Health funds are increasingly being used to support community living for severely impaired individuals. Funding is problematic in that it is rarely (if ever) assured. This has critical implications both for families and for those providing the service. One major problem is that it is extremely difficult to attract good staff to a job lacking in competitive pay as well as adequate security (Wall, 1990). Unfortunately even the most successful programs for this very needy population suffer the negative consequences of precarious funding.

Strong, Visionary and Supportive Administration.

Model programs are administered well by knowledgeable and competent people (e.g., Holmes, 1990; Kay, 1990; Wall, 1990).

Administrative staff have expertise both in efficient management and in the problems of autism. They (including Boards and Advisory Committees) are responsive to clients and staff, and to the families involved. All successful programs acknowledge the need for coordinated efforts between all parties, coupled with strong, visionary and supportive leadership. Administration works with staff in assuring better pay and benefits, and advancement within the organization. Staff are also directly involved in decision making and information exchange.

Dedicated and Knowledgeable Staff.

Exemplary programs devote substantial time to the selection and ongoing training of staff (e.g., Simonson, et al., 1990; Wall, 1990). Staff are chosen for the purpose of teaching individuals with autism, and for assuring their safety and well-being. Staff receive pre-service and regular in-service training in all aspects of autism, as well as the opportunity to attend relevant conferences. Staff learn novel teaching and behaviour management techniques (e.g., nonaversive methods), and they adopt a nonjudgemental attitude towards parents. Successful programs engage in regular staff evaluations, and they recognize the achievements of staff. Staff work with parents, administrators and professionals on behalf of people with severe and pervasive disorders.

Family Involvement.

All successful programs for people with autism were initiated by parents in the absence of any alternative services. Each program acknowledges the critical significance of a strong voluntary/parent effort, well supported by legislation and public funds. Parents also assume central administrative roles (as Board or Advisory Committee Members) in all aspects of successful programs, regardless of their particular model of service (see Special Issue on Residential Services, 1990). These programs are characterized by mutual respect of, and support for, everyone working together to produce better outcomes for this very challenging population.

Professional Services.

Exemplary programs draw heavily on the expertise of several professionals, including language pathologists, occupational therapists, physicians and psychologists (e.g., Van Bourgondien & Elgar, 1990; Simonson, et al., 1990). These programs are distinguished by the use of systematic, state-of-the-art methods of teaching and managing disruptive or inappropriate behaviours. Clients' behaviour is observed and documented carefully, for the purpose of developing individualized program plans and evaluating their effectiveness. New techniques are also developed as service providers become more knowledgeable about the problems associated with autism. This information is then disseminated in comprehensible form to families and to other service providers working with severely and pervasively disordered individuals. Professionals are involved in the training of staff, students and families, and are responsible for keeping abreast of and contributing to new advancements in the field.

Structured and Well-Staffed Programs.

Successful programs are distinguished by the amount of meaningful activity, and by the degree and flexibility of structure provided for clients (e.g., Kay, 1990; Van Bourgondien & Elgar, 1990; Wall, 1990). Staff-client ratios are high, and a workable balance in the severity of clients' impairments is maintained. Several model programs have limited growth in an attempt to assure quality of service. Staff assume the role of teacher and friend in productive, safe and attractive settings. Clients receive full-day programs designed to facilitate the development of all relevant life skills, including communication and socialization, self-care, and appropriate vocational and recreational/leisure activities. Individualized program plans are based on clients' abilities, needs and interests. Exemplary programs are continually changing in response to unforeseen needs, and to the development of better teaching and behaviour management strategies. Such programs recognize that a great deal of ongoing planning is

required to adequately and appropriately serve people with severe and pervasive handicaps.

A Mission.

Successful programs have a well-articulated mission, shared by all parties, and reflected in all training and services provided (e.g., Holmes, 1990; Wall, 1990). Clearly shared values and standards are developed and nurtured through adequate resources, and through mutual support of and respect for the many dedicated people working on behalf of those with autism or related (severe) disorders. The spirit is one of assuring that people with autism live in and enjoy the most enabling environment possible, and that they become productive and valued members of the larger community.

Concluding Remarks

"Integration" and "normalization" are the current buzz words in the deinstitutionalization movement. These terms may serve political and social goals, but two points bear emphasizing. "Integration" and "normalization" refer to ends; they say little about how those ends are to be achieved (Mesibov, 1990; Schopler & Hennike, 1990; Zigler, et al., 1990). Neither is achieved without a great deal of work and planning for people with severe and pervasive disabilities. What is needed is a plan articulating exactly how integration and normalization will evolve. We also need evidence that severely handicapped individuals are actually experiencing a better life than that provided by institutions. As goals, integration and normalization imply reasonable quality of life.

Specialized programs have worked hard to develop in all people with autism a more productive and personally satisfying existence. They are model programs precisely because of the success achieved in an otherwise largely unserved population. People with autism are both

"hard to serve" and at high risk for institutionalization. Model programs have shown that success is possible, given certain conditions. These include stable funding, a strong and supportive administration, dedicated and knowledgeable staff, family involvement, professional expertise, structured and well-staffed programs and, equally important, a mission to serve people with autism as well as possible. The shared goal is to integrate (or normalize) these individuals such that their quality of life is enhanced.

The acid test of any program is the extent to which clients' needs are met, not simply whether they are placed in the community and look normal (Mesibov, 1990; Schopler & Hennike, 1990; Zigler, et al., 1990). What is needed are criteria and a set of procedures by which to judge quality of life. Program evaluation and quality assurance should be part of any service delivery system. We need to evaluate the strengths and weaknesses in service delivery to develop more effective systems. Changes in service delivery to people with severe developmental disorders should reflect both their needs and current knowledge of the disorders in question.

Several authors have recently expressed serious concerns about the lives of developmentally disabled people and their families (e.g., Mesibov, 1990; Schopler & Hennike, 1990; Zigler, et al., 1990). Many services remain largely custodial, even though they are increasingly being offered in the "community". Existing services also typically exclude people with severe and pervasive developmental disorders. Most programs (residential, vocational or recreational) are limited in staff and expertise, and have experienced failure in serving this population. Model programs have demonstrated success, not only in integrating people with autism, but also in improving their quality of life. The knowledge gained should play a central role in the development and enhancement of services to all citizens with autism, regardless of their place of residence.

The principle of a "continuum of services" has been adopted by the North Carolina 1984 General Assembly, and is expressed in all model programs described here. A continuum of services includes both generic and specialized programs. Some specialized programs offer full-day training to both nonresidents and residents, as well as other outreach services. They also consult with generic agencies serving the same or related populations. A continuum of services that includes specialized programs assures expertise in the field of autism. Model programs embrace service, training and research. Each enhances the others. Together the three assure that people with severe and pervasive handicaps experience better outcomes than those associated with institutionalization.

Finally, information on the current status of the 802 adolescents and adults identified in the 1990 Ontario Survey is provided at the end of this book. Extrapolating from recent prevalence data on autism (Bryson, et al., 1988; Sugiyama & Abe, 1989), this represents only a fraction of those presently residing in the Province. The information provided indicates that the vast majority of the 802 individuals will require alternative community services, either immediately or in the immediate future. For many the services currently received terminate in early adulthood. In addition, many severely and multiply handicapped individuals who remain in large Provincial institutions have autism or a related disorder. The paucity of existing services, coupled with the severity of the impairments associated with autism, has created a crisis situation for many families. The major problem is that citizens in Ontario who are most vulnerable and most in need remain largely unserved.

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Recommendations

1. That a continuum of community services be developed in Ontario for adolescents and adults with severe and pervasive developmental disorders. This includes a continuum of generic and specialized residential programs, and of full-day vocational and recreational programs for both residents and nonresidents. Programs aimed at community integration need to squarely address the specific needs of people with autism or related disorders.
2. That carefully selected specialized programs be formally designated as Provincial (community) resource centres for adolescents and adults with autism. These centres should be located in different regions of the province, but should be affiliated through their shared commitment to this challenging population. Resource centres might also be affiliated with local universities and community colleges, and with other professional organizations dedicated to the well-being of severely handicapped people. Specialized resource centres should exemplify ongoing direct service, training of staff and students, and research relevant to treatment.
3. That Provincial universities and community colleges develop collaborative, interdisciplinary programs for the study of autism and related disorders. Resources would be pooled to enhance the provision of community services to affected individuals and their families. Such programs should harness the enthusiasm of students, and should facilitate from the outset the development of co-operative efforts between all parties working on behalf of severely disabled people.
4. That existing specialized programs for people with autism be adequately funded and staffed to develop their outreach services without compromising the quality of ongoing programs.
5. That new specialized programs for adolescents and adults with autism be developed, given the demonstrated need, adequate resources and a commitment to program evaluation. The focus of these programs should be educational, and should include training in communication and socialization, self-care, vocational skills and appropriate recreational/leisure activities. Both residential and full-day programs are needed, and full-day programs are required for nonresidents as well.
6. That generic programs be mandated to serve people with autism once appropriate supportive services (Provincial resource centres) are formalized and adequately staffed. Specialized resource centres should be involved in direct service themselves, and should consult with and train generic service providers working with the same or related populations.
7. That a Provincial plan be developed for the provision of community services to people with autism and related disorders. This includes a plan for how services will be provided for the many severely and multiply handicapped people who remain in large Provincial institutions. The plan needs to articulate the means by which integration/normalization will proceed, and should outline procedures for quality assurance. The plan should also provide for regular needs assessments to evaluate on an ongoing basis relative strengths and weaknesses in the community service system. An Advisory Committee consisting of all relevant parties (service

providers, government officials, professionals and families) should be established for this purpose.

8. That funding for supported community living be sought from all three Provincial Ministries (Health, Education, and Community and Social Services), particularly for severely impaired adolescents and adults. Equitable sharing of resources might assure the development of greater expertise in all relevant service providers. Liaisons between all three Ministries might also promote more effective transitions for people with autism, notably from school to the larger community, and from home to medical facilities.
9. That support for highly innovative specialized programs for people with autism be sought from Federal as well as Provincial sources. Such programs might serve as models not only in Ontario, but throughout the entire country.
10. That the Autism Society Ontario recognize exemplary programs through awards of distinction. This would require the development of a set of standards and procedures for making such evaluations.
11. That the Autism Society Ontario embark immediately on a concerted campaign to educate the public about autism. This includes relevant education of police officers, fire fighters and hospital staff.
12. That the Autism Society Ontario immediately strike a Strategic Planning Task Force to address each of the above recommendations and to develop detailed and specific plans for implementation. Once this is accomplished, a meeting should

be arranged with all relevant officials to discuss both the pressing need for the development of community services and the plans for how this might best be achieved. (The U.S. experience suggests that with a concerted effort, many of the components of exemplary service could be in place within 4-5 years).

Case Profiles

In the first section of this report, Dr. Bryson described Autism as it is presented in the literature. In the second section the needs of 802 individuals with Autism in Ontario and the services available to meet these needs were illustrated through statistical data gathered from the Survey. The following case studies were developed by members of the Adult Task Force to illustrate in more human terms Autism in Ontario. These five cases were deliberately chosen to portray the range of individuals found in the survey (see section 2).

Case Profile A:

Jack is a thirty-five year old man who is living in his parents' home in a small rural community. He is moderately handicapped by Autism. Jack enjoys watching game shows and going for long walks. He can correctly identify every model and make of car that drives down the road.

Jack went to the local public and high schools for twelve years, at a time when special education programs were not available. Until recently, he then spent his days accompanying his father as he worked the farm. His two older brothers have moved to Toronto and have families of their own. His father was seriously injured in a farm accident six months ago and has been hospitalized ever since.

On her own, his mother has difficulties as she is physically intimidated by Jack. This began with Jack perceiving his mother's discomfort with assisting him with his personal care. As Jack recognized this, the situation got progressively worse, resulting in his mother losing all control of Jack's behaviour and appearance. Emotionally, Jack's mother is having a hard time coping with this new situation.

With the help of her oldest son, Jack's mother has been meeting with the local service provider in an attempt to obtain placement in a Day Program for Jack. This has been met with sympathetic concern, but due to Jack's unstructured background it is felt that the local sheltered workshop cannot meet his needs. There are no alternatives. Jack's brother suggested that perhaps he could get a placement for Jack in Toronto, but when he contacted the Metro service providers he was met with two- to five- year long waiting lists.

Jack's mother struggles at home alone and the situation is worsening, thereby jeopardizing her physical and emotional health.

Case Profile B:

Chris turned eighteen last January. She has been in a structured school program individually tailored to meet the unique needs of Autism since her pre-school years. With the help of a Special Services at Home worker, Chris's family is able to structure her time after school and on weekends with skill development and activities. Within this high level of structure, Chris is able to cope. Her family has been reasonably satisfied with her programs and the progress she has made over the years.

Chris uses sign language to communicate. She is able to effectively communicate with her immediate family, teachers and Special Services at Home worker. In unfamiliar social situations, Chris becomes very anxious and agitated. The situation can be defused by Chris retreating to a familiar setting, or sometimes, activity.

Chris's family worries that when she leaves the school system her community's resources will not be able to maintain the degree of structure that Chris needs to cope. The local Association for Community Living has several options for Day Programming, all of which are based on unstructured group activities such as a large sheltered workshop,

minimally supervised work crews and a Life Skills Program. The staffing ratios of these programs are approximately ten clients per one staff member. With the exception of the sheltered workshops, these programs are not full days.

For fifteen years Chris's parents have been actively involved with their local chapter of the Autism Society Ontario to establish community-based services for children with Autism. This has been a long struggle. As Chris approaches adulthood, the focus of their advocacy has shifted to the need for structured, individualized adult programs. They are currently working hard to convince the Association for Community Living and the local government officials of the need for this additional service.

Case Profile C:

John is thirty-one years of age and is currently residing with his aging parents. He is verbal and of near normal intelligence, although his interactions with others are strikingly awkward. John has a myriad of rituals, including compulsive touching and a running, disk jockey-like commentary of his activities. His conversations are limited to a few repetitive themes, typically involuntary preoccupations with cleanliness, food preferences and his failure to obtain a girlfriend. John suffers significant anxiety, as well as periodic episodes of depression.

Several attempts to obtain services for John have failed. He is either denied services because of exclusionary criteria, or services are discontinued on the grounds that he has neither the "right" attitude nor the necessary skills for vocational or residential placement. Unfortunately, such problems are an inherent part of John's developmental disability. His apparent intelligence is deceptive. John has extreme difficulty using knowledge in any practical way, as

indicated, for example, by his inability to solve problems, to make a change or to cope with any changes in his routine.

Case Profile D:

Kevin is twenty-eight years old and has lived in a large institution for the past twenty-one years. He is severely and multiply impaired and has no effective way of communicating. As a child he was diagnosed as having early childhood schizophrenia.

Kevin was institutionalized because of severe temper tantrums, self-abuse, and unusual sleep disturbances. His parents tried to cope but, when the safety of younger children in the house became an issue, they reluctantly admitted him.

Kevin communicates some of his desires and frustrations by gesturing, crying and slapping his face. Staff have tried to introduce signing and a picture system but Kevin has not responded to these attempts. He has learned dressing, eating, and toileting tasks and he does work assembling pens for about two hours a day.

Kevin takes various forms of medication several times a day. These include: psychotropic drugs to reduce aggression, anti-seizure medication to control epilepsy, and medication to help him sleep well.

Since Kevin has lived in the institution, he has had episodic outbursts of aggression (mostly directed at the smaller residents) and self-abuse (has required stitches on a number of occasions). Kevin suffers from pica (ingesting cigarette butts, paper and twigs) and engages in anal poking. Due to his poor health habits, he has had repeated bouts of intestinal parasites and has required surgery to clear a bowel obstruction.

The institution in which Kevin resides has been designated to be depopulated within the next few years. Kevin is on a waiting list for a placement within his home community.

services and none as yet have been sought on a fees-for-service basis. This lack of support has led to a high level of burnout amongst the staff members who work with Dennis.

Case Profile E:

Dennis is a fifty-one year old man who is living in a group home with four other adults outside of Toronto. As a child he was placed in a large institution by his parents on the advice of their family doctor. Dennis lived in this institution for thirty years, then moved to a large group home where he stayed for ten years and moved to this group home four years ago. Dennis has never had a formal assessment or diagnosis of his abilities but the term "mentally handicapped with autistic tendencies" has been used when referring to his condition.

Dennis goes out with the other members of his household to the sheltered workshop during the week and in the evenings, and on weekends he sits in his room alone watching game shows and sorting bottle caps. At Christmas and on his birthday, his mother and one of his sisters will come to take him to their home for dinner.

Dennis communicates sparingly with a picture wallet that the staff of the group home have made for him. He is a very quiet man most of the time but finds any slight change in his routine or environment hard to cope with. At such time he becomes very aggressive to himself and property and all attempts to communicate with Dennis seem to break down. The staff members who work with him do not know how to prevent these outbursts from happening or how to deal with them when they do. They are frustrated because Dennis is, and will continue to be, exposed to change on a regular basis as there is so much turnover in the staffs of the programs he is in as well as the changes within the programs themselves. The staff have requested consultation from speech-language services and behaviour therapy but the agency does not provide these

ADULT TASK FORCE SURVEY, 1990

Introduction

At its first meeting on April 7, 1990, the Adult Task Force of the Ontario Society for Autistic Citizens (since renamed Autism Society Ontario) decided to undertake a survey of adults and older adolescents with autism and pervasive developmental disorder (PDD). It was decided to collect data for all such persons born 1974 or earlier, as to their present services and perceived needs. Assuming that such information might already be available from parents who were members of OSAC from the OSAC-Chedoke 1988 survey results, the 1990 survey was directed mainly to agencies and school boards about their clients and referrals. Using the survey form designed by Barbara Donaldson of Kerry's Place and Susan Day-Fragiadakis of the Geneva Centre, the OSAC Office mailed out survey packages to over 400 agencies and 130 school boards.

By October 31, 1990, completed forms had been received back from 88 agencies and 32 school boards. Some 62 other agencies reported no autism/PDD clients or declined to co-operate while 38 school boards declined or reported no autism/PDD clients. A supplementary mailing to OSAC parent members in November-December 1990 boosted the percentage of parent responses to 10 per cent.

The data were entered in dBASE IV by Victoria Bloomfield, using a structure designed by Elaine Williams and Elizabeth Bloomfield. Elizabeth was responsible for the counts and cross tabulations presented here. After controlling for duplicate records and forms submitted in error for younger children, the ADULT database held 802 records when the final counts and tabulations were made on February 1, 1991.

How good is the 1990 survey in representing the present status and the present and future needs of adults with autism in Ontario? This question may be answered on various levels. We should note to begin with, that the survey was not taken of any deliberate sample of the whole adult autistic population, as we were concerned to trace every adult with autism/PDD that we possibly could. The total number of 802 subjects in this survey is an impressive figure. But we have only a proportion of all those who probably have autism/PDD in Ontario.

What proportion has our survey captured of the statistically likely number of all adults with autism/PDD? This depends on the rates of autism/PDD in the population that have been established by epidemiological studies. For classic autism, the incidence rate was traditionally taken to be 4.5 persons with autism per 10,000 of the whole population. More recent studies have established an incidence for autism of 13 per 10,000 and, if PDD is also included, the rate is as high as 21 per 10,000.

If we consider all persons born between 1930 and 1974, we identified 802 cases in relation to a total population of about 5,984,660 in these age-groups in Ontario as a whole.

<i>At a rate of 4.5 per 10,000 we would expect 2,693, of whom our</i>	<i>survey</i>
<i>found 29.8 %</i>	
<i>At a rate of 13 per 10,000 we would expect 7,780 of whom our</i>	<i>survey</i>
<i>found 10.3%</i>	
<i>At a rate of 21 per 10,000 we would expect 12,568 of whom our</i>	<i>survey</i>
<i>found 6.4 %</i>	

People who are now over 40 (born before 1950) are less likely to have been diagnosed autistic as young children, so the incidence rates are understandably lower for them. For persons who are now younger adults, such as those born in the years 1967-1971, an autism diagnosis was more likely when they were young children. The survey identified 229 young adults born 1967-1971 with autism/PDD, in relation to the total Ontario population of 689,165 in this age group.

For the age group born 1967-1971:
 At a rate of 4.5 per 10,000 we would expect 310,
 of whom our survey found 73.9 %
 At a rate of 13 per 10,000 we would expect 896,
 of whom our survey found 25.5 %
 At a rate of 21 per 10,000 we would expect 1,447,
 of whom our survey found 15.8 %

The survey data should be interpreted with some care, as some sections of the questionnaire were not completed for some clients. This is especially apparent on the last page of the "Agency" form, where all the final questions are dependent on the major question: "In the next two years, will this client need to seek services elsewhere?" Agencies that expected to continue caring for a client were thus not cued to mention any support services that might enhance or offset inadequacies of the present placement. Some agency correspondents remarked in letters on the general desirability of, for example, programs to enhance communication skills. But this is not reflected properly in the data. Moreover, the "Referral" form did not include about half the survey questions, so adults traced only as referrals are not as well covered as those who were direct clients of service agencies.

Some survey forms were returned without all questions answered. The percentages of "unknown" responses to specific questions in the survey were as follows:

Gender	0.9
Present living situation	1.2
Age	1.4
Location	2.1
Verbal/non-verbal	3.6
Whether in day program	2.8
Appropriateness of present living setting	3.2
Appropriateness of day program	4.1
IQ level	6.0
Perceived need for services "elsewhere" "in next two years"	20.8

The large percentage of records completed by agencies could be somewhat biased, especially in the responses to questions that might seem to imply some criticism of the present placement. For clients in institutions, for example, 55 per cent were said to be in appropriate day programs. However the brief descriptions of such programs suggest that many of them were quite limited, such as one afternoon a week, and only vestiges of what other people might consider adequate. The perception of clients' needs depends heavily on the knowledge base of the person completing the form.

This report consists of basic counts and cross tabulations of variables believed to be of interest to those who are planning and advocating for appropriate services for adults with autism. At the beginning of each table, the survey question may be quoted, with comments on the ways the question was answered if these seem relevant to understanding the responses. Numbers and percentage are usually presented, the percentages being calculated of the total number of actual responses to that question.

ADULT TASK FORCE SURVEY, 1990

The 1990 survey of the needs of adults with autism/PDD was based mainly on the responses of agency staff -- for their own clients or for persons on their referral list. In all, agency and school board personnel described nearly nine in every ten of the persons found in the survey.

In some cases, information about a specific person may have been received from more than one source -- perhaps from parents, a school board and from one or more service agencies. Using a combination of the subject's initials, year of birth, and geographical location, we were able to control for such duplicates and to ensure that only one set of data was entered for each specific individual. In such cases, the questionnaire with the most complete information was chosen.

*Table 1
Types of Respondents Completing Survey*

	#	%
Agencies: for own clients	507	63.2
- in facilities	135	5.9
- in group homes	222	27.7
- in family homes	101	12.6
- all others	49	6.1
Agencies: for referrals	153	19.1
School boards	61	7.6
Parents	<u>81</u>	<u>10.1</u>
total	802	100.0

What are some of the demographic characteristics of the adults in the 1990 survey? The gender balance of subjects in the 1990 survey (Table 2) conforms quite well to that expected among people with autism -- 3.5 males to every female. The proportions in the various age groups (Table 3) illustrate the effect of better diagnostic and assessment services in the more recent period. Well over half the subjects were 25 years or under at the time of the survey.

*Table 2
Gender*

	#	%
Male	605	76.1
Female	<u>190</u>	<u>23.9</u>
total	795	100.0
not stated: 7		

*Table 3
Age Groups*

<u>Year of birth</u>	#	%
<1940	18	2.3
1940-1944	12	1.5
1945-1949	26	3.3
1950-1954	51	6.4
1955-1959	93	11.8
1960-1964	143	18.1
1965-1969	196	24.8
1970-1974	<u>252</u>	<u>31.8</u>
total	791	100.0
not stated: 11		

IQ, Communication Skills and Dual Diagnoses

Intelligence or functioning level is notoriously hard to measure in people with autism. The pattern of estimates made by those who completed the survey questionnaires (Table 4) conforms well to what has been generally described in the literature. Between one third and one half of the survey subjects were reported non-verbal or to have communication skills that were inadequate for daily living (Table 5).

*Table 4
IQ Level*

(these ranges were prompted; respondents were asked "if unknown, please estimate")

	#	%
>85 normal	44	5.8
71-85 mild	179	17.1
55-70 moderate	259	34.3
<55 severe	<u>322</u>	<u>42.7</u>
total	754	100.0
not stated: 48		

*Table 5
Communication Skills*

(respondents were asked to "check all that apply")

	#	%
Verbal	399	51.6
Non-verbal	<u>374</u>	<u>48.4</u>
total	<u>773</u>	100.0
not stated: 29		
Augmentative communic. (sign, PIC, Bliss)	191	23.8
Communication skills inadequate for daily needs	238	29.7

Dual Diagnosis and Health Complications

Significant numbers of adults and adolescents in our survey group have dual diagnosis problems (Table 6). More than one fifth reported seizure disorders (epilepsy) and nearly three-tenths some sort of psychiatric disorder (such as bi-polar, depression, anxiety or schizophrenia). Nearly half of all the adults and adolescents in the survey were considered to have severe behaviour problems. Two of every three persons in the survey had at least one of the three kinds of disorders set out in Table 6, while nearly one in four suffered from at least two such complications in addition to autism.

Table 6
Health Complications and Problems

(These types were prompted; respondents were asked to "check all that apply" and to state any "others")

	#	%
Seizure disorders	171	21.3
Psychiatric (manic, bi-polar, schizophrenia, depression, anxiety)	227	28.3
Severe behaviour problem	357	44.5
At least one of above	529	66.0
Two or more of above	188	23.4

Other health complications reported:

- Celiac disease*
- Asperger's syndrome*
- Rett's syndrome*
- Cerebral palsy*
- Physically disabled*

Present Living Situation

Where were the adults and adolescents identified in our survey living? The largest numbers of subjects were in group homes, the family home, and facilities (Table 7). More than four in ten answered "No" to the question "Is the present living situation appropriate?" (Table 8), and some of the problems are summarized in Table 9. Table 20 later in this report expresses the relationship between present living situation and the perception of appropriateness.

*Table 7
Present Living Situation*

	#	%
Family home	223	28.1
Foster home	26	3.3
Group home	309	39.0
Institution	200	25.2
SIL	17	2.1
Apartment	2	0.2
Independent	6	0.7
Other	<u>9</u>	<u>1.4</u>
total	792	100.0
not stated:	10	

*Table 8
Is Present Living Situation Appropriate?*

	#	%
Yes	446	57.5
No	<u>330</u>	<u>42.5</u>
total	776	100.0
not stated:	26	

Table 9

Problems of Present Living Situation

(These specific responses were unprompted. An average of 1.8 problems was stated for each client reporting inappropriate living setting at present. Percentages are calculated of total number of 330 reporting inappropriate living setting).

	#	%
Too institutional	137	41.5
Needs adult placement	97	29.4
Unmet needs	87	26.4
Parents aging	57	17.3
Needs structure/supervn	49	14.8
Disruptive behaviour	27	8.2
Staff ratio inadequate	19	5.7
Staff skills inadequate	18	5.4
Needs independence	9	2.7
Incompatible disabilities	6	1.8
Parents want placement	3	0.9
Other	104	31.5

*"Other" included:
Want group home setting (17)
Institution closing; need group home setting (11)
Serious aggressive behaviours (11)
Present placement is only temporary (6)
Parents are ill and elderly
Need to live more independently (5)
Many other responses indicate that parents and family cannot cope without support services*

Present Day Programs

The survey asked what types of day programs were available and used. A large majority of adults and adolescents reported some type of day program, 45 per cent being still in school and 57 per cent in some kinds of vocational or life skills program. A day program was not defined for the survey, and respondents seem to have taken it to include quite informal activities that might be arranged for only an hour or two each week.

Table 10
Present Day Program

	#	%
Yes	647	83.1
No	<u>132</u>	<u>16.9</u>
total	779	100.0
not stated: 23		

Table 11
Type of Present Day Program

(These types were prompted. An average of 1.6 day programs was reported for each client reporting any day program. Percentages are calculated of the total 647 persons reporting any day program).

	#	%
School	289	44.7
Vocational/lifeskills	372	57.5
Supported employment	11	1.7
Competitive employment	9	1.4
Other	100	15.5

"Other" included walks around grounds, chapel, recreation, music therapy, word program, rug hooking and stamping, a 1:1 program operating out of residential setting.

Table 12
Is Present Day Program Appropriate?

(Percentages are calculated of those reporting any day program and responding to this question; 132 respondents had no day program)

	#	%
Yes	515	83.9
No	<u>99</u>	<u>16.1</u>
total	614	100.0
not stated: 33		

Table 13
Problems of Present Day Programs

(These responses were unprompted. An average of 1.7 problems was stated for each client reporting inappropriate day program at present. Percentages are calculated of the total 99 reporting inappropriate day programs)

	#	%
Needs more structure	53	53.5
Needs challenge	48	48.5
Needs adult placement	15	15.1
Staff ratio inadequate	14	14.1
Staff skills inadequate	13	13.1
Incompatible disabilities	7	7.1
Other	15	15.1

"Other" and general comments included:

Needs more assistance with communication (12)

More supervision needed (7)

Needs more normal activities to do (10)

Needs competitive employment with pay

Needs more self-help skills

"All gains over past few years are being lost"

"Has too much time to do nothing"

"Has to have some reason to get up in the morning"

"Needs activities to give a sense of self-worth"

Need for New Services in Next Two Years

An important question was asked on all forms except that used by agencies for persons on their referral lists: "In the next two years, will this client need to seek services elsewhere (too old for program, inappropriate program, etc)". Only if respondents answered Yes to this question, were subsequent questions answered as well.

Table 14
Perceived Need for "Services Elsewhere" in Next Two Years

	#	%
Yes	422	66.5
No	<u>213</u>	<u>33.5</u>
	635	100.0
not stated: 167 (mainly referrals)		

Table 15
Type of New Living Situation Needed in Next Two Years
(These options were prompted. Percentages are calculated in relation to the total 359 for whom new living situations were reported to be needed)

	#	%
Group home specialized in Autism/PDD	137	38.2
Group home generic	102	28.4
Supported Independent Living Project	43	12.0
Community support to stay in family home	42	11.7
Foster home	7	1.9
Institution	1	0.3
Group home near family	2	0.5
Smaller setting w. structure	15	4.2
Other	10	2.8

Table 16
New Day Programs Needed

(Prompted options; average of 1.31 new programs needed for each client stating a need; percentages calculated of total 422 clients stated to need new programs in next two years)

	#	%
Sheltered workshop	106	25.1
Prevoc/lifeskills	214	50.7
Supported employment	150	35.5
Competitive employment	30	7.1
Postsecondary education	18	4.2
Other	36	8.5

*Other day programs needed:
 Lifeskills for low-functioning adults
 Communication and language training
 Functional activity that gives person sense of self-worth*

Table 17
Other Support Needed in Next Two Years

(Prompted options except for "social skills" which may be under-represented; average of 2.7 new programs needed for each client stating a need; percentages calculated of total 422 clients stated to need new programs in next two years)

	#	%
Sex counselling	91	21.6
Legal services	32	7.6
Monitoring of drugs	87	20.6
Case management	143	33.9
Respite care	82	19.4
Behaviour management	175	41.5
Leisure skills	243	57.6
Communication skills	230	54.5
Social skills	20	4.7
Other	41	9.7

Geographical Distribution of Ontario Adults with Autism

Respondents were asked to state home county, region or district, but this information was not provided very well. We entered the correct county/region/district corresponding to the given home locality or city. If this information was not provided, we used the location of the residential agency serving the client.

Numbers in each county/region were related to total population. Very low to low frequencies are noted for Grey, Middlesex, Prescott-Russell, Elgin, Victoria, Stormont-D-G, Essex, Peel, Halton, Renfrew, Leeds-Grenville -- all of which had under half the provincial mean frequency. Very high frequencies are noted for Brant (mainly because the Sanitarium did not state home counties of most clients and they were therefore counted in Brant), and for Thunder Bay and Kenora -- all with over twice the provincial mean. No responses were received from the Districts of Haliburton or Rainy River districts. Seventeen responses could not be located in an Ontario county (4 stated just "Central" region, 3 only Montreal, 1 Victoria BC, 4 stated "unknown" location).

Table 18

Location of 1990 survey respondents by Ontario county/region/district

	#	1988 pop.
Algoma	8	117,339
Brant	24	102,085
Bruce	9	57,199
Cochrane	9	84,846
Dufferin	3	34,452
Durham	30	347,837
Elgin	1	69,174
Essex	9	314,952
Frontenac	12	119,332
Grey	1	75,157
Haldimand-Norfolk	9	89,225
Halton	12	281,668

Hamilton-Wentworth	39	429,466
Hastings	12	106,240
Huron	5	55,589
Kenora	8	35,150
Kent	15	105,176
Lambton	10	119,528
Lanark	13	49,483
Leeds-Grenville	4	83,166
Lennox-Addington	5	32,998
Manitoulin	1	6,771
Metro Toronto	164	2,133,559
Middlesex	9	344,586
Muskoka	4	39,958
Niagara	42	365,197
Nipissing	9	51,313
Northumberland	6	67,232
Ottawa-Carleton	78	623,135
Oxford	9	84,008
Parry Sound	3	30,138
Peel	20	608,327
Perth	5	66,226
Peterborough	12	105,493
Prescott-Russell	1	59,138
Prince Edward	6	21,793
Renfrew	5	85,953
Simcoe	44	241,694
Stormont-D-G	7	101,978
Sudbury	10	168,677
Timiskaming	1	35,741
Thunder Bay	29	140,951
Victoria	2	55,132
Waterloo	32	342,030
Wellington	15	143,778
York	33	409,292

ADULT TASK FORCE SURVEY
cross tabulations of final data

Table 20
Appropriateness of Living Setting by Type of Current Living Setting

	<u>Approp</u>		<u>Inapprop</u>		<u>Unknown</u>		<u>Total</u>	
	#	%	#	%	#	%	#	%
<u>Present Setting</u>								
Family home	122	54.7	95	44.8	6	2.7	173	100.0
Foster home	19	73.1	7	26.9			26	100.0
Group home	235	76.1	64	20.7	10	3.2	309	100.0
Institution	45	22.5	150	75.0	5	2.5	200	100.0
SIL	14	82.3	3	17.7			17	100.0

Table 21
Appropriateness of Day Program by Type of Current Day Program

	<u>Approp</u>		<u>Inapprop</u>		<u>Unknown</u>		<u>Total</u>	
	#	%	#	%	#	%	#	%
<u>Present Setting</u>								
Any day program	515	79.6	99	15.3	33	5.1	647	100.0
School	229	79.2	41	14.2	19	6.6	289	100.0
Vocational/lifeskills	300	80.6	57	15.3	15	4.0	372	100.0
Supported employment	10	90.9	1	9.1			11	100.0
Competitive employmt	9	100.0					9	100.0
Other	73	73.0	22	22.0	5	5.0	100	100.0

Table 22
Appropriateness of Current Services by IQ Level

(percentages calculated of total numbers at each IQ level; Tables 22 and 23 are complementary for each variable; note that assessments of appropriateness were not made for some records at each IQ level)

IQ		<u>Approp Living</u>		<u>Approp Day Program</u>		<u>Adequate comm.skills</u>		<u>No Need in Next 2 years</u>	
		#	%	#	%	#	%	#	%
>85	normal	26	59.0	29	65.9	40	90.9	11	25.0
71-85	mild	71	55.0	89	69.0	112	86.8	26	20.1
55-70	moderate	155	59.8	184	71.0	190	73.4	80	30.9
<55	severe	171	53.1	228	70.8	184	57.1	90	27.9

Table 23
Inappropriateness of Current Services by IQ Level

(percentages calculated of total numbers at each IQ level; Tables 22 and 23 are complementary for each variable)

IQ		<u>Inapprop Living</u>		<u>Inapprop Day Program</u>		<u>Inadequate comm.skills</u>		<u>Need in Next 2 years</u>	
		#	%	#	%	#	%	#	%
>85	normal	15	34.1	11	25.0	4	9.1	27	61.4
71-85	mild	55	42.6	31	24.0	17	13.2	71	55.0
55-70	moderate	97	37.4	63	24.3	69	26.6	138	53.3
<55	severe	142	44.1	70	21.7	137	42.5	170	52.8

Table 24
Health/Behaviour Problems by IQ Level

(percentages calculated of total numbers at each IQ level)

IQ	Seizures		Psychiatric Disorders		Severe Behaviour	
	#	%	#	%	#	%
>85 normal	-	-	11	25.0	5	11.4
71-85 mild	19	14.7	51	39.5	41	31.8
55-70 moderate	38	14.7	93	35.9	112	43.2
<55 severe	102	31.7	67	20.8	178	55.3

Table 25
Types of Present Living Situations by Age Group

Year of birth	Family Home	Foster Home	Group Home	Institutn	SIL	Apartmt	Independt	Other
	#	#	#	#	#	#	#	#
<1940	1	-	5	12	-	-	-	-
1940-1949	4	1	8	21	2	-	1	-
1950-1959	14	3	35	81	6	1	2	1
1960-1969	96	8	143	74	6	1	2	4
1970-1974	107	14	112	10	3	-	-	3

Table 26
Types of Present Day Programs by Age Group

<u>Year of birth</u>	<u>ANY DAY PROGRAM</u> #	<u>School</u> #	<u>Voc.Train Lifeskills</u> #	<u>Support Employmt</u> #	<u>Compet. Employmt</u> #	<u>Other</u> #
<1940	16	1	14	-	-	-
1940-1949	28	-	28	-	-	1
1950-1959	120	11	106	2	2	4
1960-1969	245	55	185	7	5	19
1970-1974	231	220	36	2	1	16

Table 27
Appropriateness of Current Services by Age Group

(percentages calculated of total numbers in each age group; Tables 27 and 28 are complementary for each variable; assessments of appropriateness were not made for a few records at each level)

<u>Year of birth</u>	<u>Approp Living</u>		<u>Approp Day Program</u>		<u>Adequate comm.skills</u>		<u>No Need in Next 2 years</u>	
	#	%	#	%	#	%	#	%
<1940	7	38.9	16	88.9	14	77.7	5	27.8
1940-1949	12	31.6	27	71.0	29	76.3	11	28.9
1950-1959	67	46.5	112	77.8	97	62.5	42	29.2
1960-1969	187	55.2	195	57.5	230	67.8	109	32.1
1970-1974	165	65.5	197	78.2	181	71.8	43	17.1

Table 28
Inappropriateness of Current Services by Age Group

(percentages calculated of total numbers in each age group; Tables 27 and 28 are complementary for each variable; assessments of appropriateness were not made for a few records at each level)

<u>Year of birth</u>	<u>Inapprop Living</u>		<u>Inapprop Day Program</u>		<u>Inadequate comm.skills</u>		<u>Need in Next 2 years</u>	
	#	%	#	%	#	%	#	%
<1940	11	61.1	2	11.1	4	22.2	13	72.2
1940-1949	24	63.1	8	21.0	9	23.7	24	63.2
1950-1959	75	52.1	27	18.7	47	32.6	72	50.0
1960-1969	142	41.9	109	32.1	107	31.6	148	43.7
1970-1974	77	30.5	40	15.9	69	27.4	162	64.3

Table 29
 Perception of General Needs by Type of Respondent

(Note: forms used by referral agencies did not normally include question about need within next two years)

<u>Next 2 years</u> <u>Respondent type</u>	<u>Living</u>	<u>Total</u>		<u>Need in</u>				<u>Inapprop</u>	<u>Inapprop/No</u>
		<u>Day</u>	<u>Program</u>	<u>%</u>	<u>#</u>	<u>%</u>	<u>#</u>	<u>%</u>	
Parents		81	76	93.8	31	38.3	31	38.3	
Agencies: facilities		135	95	74.1	95	74.1	44	32.6	
Agencies: group homes		222	108	48.6	33	14.9	46	20.7	
Agencies: family		101	75	74.3	39	38.6	26	25.7	
Agencies: referrals		153	6	3.9	112	74.2	69	45.1	
School boards		61	32	53.3	6	10.0	1	1.7	
All others (incl. agencies with clients in foster/SIL/indepndt/ misc. situations)		49	30	61.2	14	28.6	17	34.7	
Totals for type of need			422		330		231		

Table 30
IQ Estimate by Type of Respondent

(percentages may not add up as a small number of respondents did not estimate IQ level)

<u>Respondent type</u>	<u>Total</u>		<u>Normal</u>		<u>Mild</u>		<u>Moderate</u>		<u>Severe</u>	
	#		#	%	#	%	#	%	#	%
Parents	81		12	14.8	21	25.9	24	29.6	17	21.0
Agencies: facilities	135		-	-	12	7.4	31	23.0	90	66.7
Agencies: group homes	222		6	2.7	27	12.3	87	39.2	90	40.5
Agencies: family home	101		12	11.9	21	20.8	35	34.6	29	28.7
Agencies: referrals	153		6	3.9	29	18.9	40	26.1	58	37.9
School boards	61		3	5.0	10	16.7	25	41.7	22	36.7
All others (incl.	49		5	10.2	9	18.4	17	34.7	16	32.6

Table 31
Perception of New Living Situation Needed by Type of Respondent

(Only some responses recommended a specific new living situation: figures in brackets following each type of respondent refer to total numbers of responses that did recommend a new living situation. "Family" stands for "Community support to remain in family home"; GH stands for "Group home" and GH:Spec stands for "Group home specializing in Autism/PDD". The types of new living situation set out in this table were the only stated options on the questionnaire; a few responses chose "other" forms such as "group home near family" or "smaller setting with structure").

<u>Respondent type</u>	<u>Type of New Living Situation</u>						
	<u>Total</u> #	<u>Family</u> #	<u>Foster</u> #	<u>GH:Generic</u> #	<u>GH:Spec</u> #	<u>SIL</u> #	<u>Facility</u> #
Parents	71	17	-	5	34	15	-
Agencies: facilities	75	-	-	56	17	2	-
Agencies: group homes	59	1	1	14	40	2	1
Agencies: family home	68	18	-	13	26	11	-
All others (incl. agencies with clients in foster/SIL/indepndt)	59	6	6	14	20	13	-
Totals for each type of new living situation		42	7	102	137	43	1

Table 32
Type of Present Living Situation by IQ Estimate

(percentages may not add up as a small number of respondents did not estimate IQ level)

<u>Present Setting</u>	<u>Total</u>	<u>Normal</u>		<u>Mild</u>		<u>Moderate</u>		<u>Severe</u>	
	#	#	%	#	%	#	%	#	%
Family home	223	24	10.8	55	24.7	71	31.8	56	25.1
Foster home	26	2	7.7	2	7.7	11	42.3	9	34.6
Group home	309	9	2.9	41	13.3	117	37.9	125	40.4
Institution	200	2	1.0	20	10.0	47	23.5	122	61.0
SIL	17			7	41.2	7	41.2	3	17.6
Apartment	2					1	50.0	1	50.0
Independent	6								

Table 33
Type of Present Day Program by IQ Estimate

(percentages may not add up as 48 did not estimate IQ level and 23 did not specify whether in day program; note also that clients with day programs had average of 1.6 programs per client)

<u>Present Setting</u>	<u>Total</u>	<u>Normal</u>		<u>Mild</u>		<u>Moderate</u>		<u>Severe</u>	
	#	#	%	#	%	#	%	#	%
School	289	17	5.9	41	14.2	106	36.7	112	38.7
Vocation/life skills	372	12	3.2	68	18.3	127	34.1	148	39.8
Support. Employmt	11			5	45.4	5	45.4		
Compet. Employmt	9	6	66.7	3	33.3				
Other	100			7	41.2	7	41.2	3	17.6
TOTAL WITH day program	647	34	15.4	109	16.8	214	33.1	258	39.8
NO Day Program	132	8	6.1	19	14.4	40	30.3	56	42.4

Table 34
IQ Level by Present Living Situation

(percentages calculated of total numbers at each IQ level)

IQ		<u>Family Home</u>		<u>Foster Home</u>		<u>Group Home</u>		<u>Institut</u>		<u>Other</u>	
		#	%	#	%	#	%	#	%	#	%
>85	normal	24	54.5	2	4.5	9	20.4	2	4.5	4	9.1
71-85	mild	55	30.7	2	1.1	41	22.9	20	11.2	9	5.0
55-70	moderate	71	27.4	11	3.9	117	45.2	47	18.1	8	3.1
<55	severe	56	17.4	9	2.8	125	38.8	122	37.9	4	1.2

Table 35
IQ Level by Availability of Present Day Program

(percentages calculated of total numbers at each IQ level; 23 responses did not state whether in day program and 48 did not specify IQ level)

IQ		<u>ANY DAY PROGRAM</u>		<u>NO DAY PROGRAM</u>	
		#	%	#	%
>85	normal	34	77.3	8	18.2
71-85	mild	109	60.9	19	20.6
55-70	moderate	214	82.6	40	15.4
<55	severe	258	80.1	56	17.4

Table 36
IQ Level by Type of Present Day Program

(percentages calculated of total numbers at each IQ level; 23 responses did not state whether in day program and 48 did not specify IQ level; various "other" types defy categorization)

<u>IQ</u>	<u>School</u>		<u>Voc/life sk</u>		<u>Supp. emp.</u>		<u>Comp. emp.</u>	
	#	%	#	%	#	%	#	%
>85 normal	17	38.6	12	27.3			6	13.6
71-85 mild	41	22.9	68	38.6	5	2.3	3	1.7
55-70 moderate	106	40.9	127	43.9	5	1.7		
<55 severe	112	34.8	148	46.0				

Table 37
Present Day Program by Present Living Setting

<u>Present Setting</u>	<u>NO DAY</u>	<u>School</u>	<u>Voc.Train</u>	<u>Support</u>	<u>Compet.</u>
	<u>PROGRAM</u>		<u>Lifeskills</u>	<u>Employmt</u>	<u>Employmt</u>
	#	#	#	#	#
Family home	39	117	71	4	4
Foster home	1	-	-	-	-
Group home	27	130	168	5	-
Institution	53	15	109	-	-
SIL	3	3	7	2	2
Apartment	-	-	2	-	-
Independent	2	-	1	-	-
Other	4		4	3	

Table 38
Dual and Multiple Health/Behaviour Problems

Of the 802 cases in the ADULT database:

109 adults have both Psychiatric Disorders and Severe Behaviour Problems

84 adults have both Seizures and Severe Behaviour Problems

31 adults have both Seizures and Psychiatric Disorders

23 adults have all of: Psychiatric Disorders, Severe Behaviour Problems and Seizures (these cases would be included in the above "dual diagnoses")

100 adults combine NO DAY PROGRAM with at least one of: Psychiatric Disorders, Severe Behaviour Problems and Seizures (4 of these adults suffered from all three kinds of problems).

127 adults living in FAMILY HOME have at least one of: Psychiatric Disorders, Severe Behaviour Problems and Seizures (3 of these adults suffered from all three kinds of problems).

158 adults living in INSTITUTIONS have at least one of: Psychiatric Disorders, Severe Behaviour Problems and Seizures (10 of these adults suffered from all three kinds of problems).

238 adults living in GROUP HOMES have at least one of: Psychiatric Disorders, Severe Behaviour Problems and Seizures (9 of these adults suffered from all three kinds of problems).