

**WATERLOO-WELLINGTON AUTISM SERVICES
SUMMARY OF PROPOSED SERVICE MODEL**
**drafted by Dr Susan E. Bryson, York University,
Honorary Director and Consultant**
with members of the WWAS Board of Directors
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Statement of the Problem

Parents and professionals, now active in Waterloo-Wellington Autism Services (WWAS), have been working for 20 years to obtain community services for people with autism and related pervasive developmental disorders (PDD). In this region, like many others, adults with autism are typically denied access to community services, on the grounds that neither sufficient staff nor expertise exists. The situation in Waterloo-Wellington has now reached crisis proportions. There are 61 identified adults with autism in the region (Report of the Adult Task Force, 1991; WWAS Needs Survey, 1992). Of these, 26 are now in Schedule I facilities or other institutions, 14 live in their family homes and 17 are in group homes. Of the 51 adults whose needs in the immediate or near future are known to us, 74 percent require new or substantially improved residential services and 82 percent require new or improved day/vocational programs.

The crisis in Waterloo-Wellington for adults with autism is exacerbated by several factors, notably:

- attempts to return residents from agencies outside the region,
- planned closing of Schedule 1 facilities,
- the continual graduation of adults from school programs into a service void,
- prohibitively long waiting lists of people with developmental handicaps, both for residential (321) and day/vocational programs (107) in the region, and
- the difficulties, expressed by local agencies, in managing the few clients with autism they do serve.

Individuals and families in Waterloo-Wellington continue to be traumatized from being shunted from agency to agency, with little or no help. The burden of suffering for all family members is immeasurable, and aging parents are simply no longer able to cope. The ongoing failure of the existing programs to accommodate adults with autism attests to their special and challenging needs.

We propose a model of an effective range of direct and outreach services, based on the findings of proven programs for adults with autism in other regions. We are determined to set up our programs for success, focusing on the needs and potential strengths of individual clients so that each can develop the greatest degree of independence in life and work skills.

Client characteristics and needs

Autism is a life-long disorder, now considered part of the spectrum of pervasive developmental disorders (PDD; APA, 1984). These disorders are defined by profound impairments in the development of social, communicative and thinking/imaginative functions. Many people with autism have no speech, and have difficulty understanding what is said. Affected individuals suffer multiple fears or anxieties, any form of change is experienced as overwhelming, and their activities are restricted largely to a few repetitive and idiosyncratic behaviours (e.g., head-banging, lining objects up in a particular order, or recurrent thoughts of contamination). Severe behaviour problems are common, as is the presence of additional psychiatric and/or medical problems (e.g., bipolar depression, epilepsy and blindness). People with autism are distinguished most from other developmentally disabled groups by their extreme difficulties in acquiring any functional or adaptive (daily living) skills (Jacobson & Ackerman, 1990).

An exceptionally high proportion of Waterloo-Wellington adults with autism is amongst the most challenging or "hard-to-serve". Of the 61 identified, forty percent are reportedly within the severe to profound ranges of cognitive and adaptive functioning (Report of the Adult Task Force, 1991; WWAS Needs Survey, 1992). Forty-six percent have no speech, nor any other means of communicating effectively. Forty-nine percent exhibit various challenging behaviours, including aggression against others and/or property, self-injurious behaviours, severe eating and/or sleeping disorders, and other psychiatric or medical illnesses. Families are understandably under tremendous strain in caring for adults with this degree of impairment. In the absence of community services, the well-being of all family members, including those with autism, remains at high risk.

The needs of adults with autism are both diverse and challenging. Community services must be designed to accommodate and be responsive to these needs. This requires sensitive and highly individualized programming that addresses all aspects of the disorder. Of paramount

importance are the person's needs for (1) an effective means of communicating, (2) a non-threatening, highly structured and predictable environment, (3) assistance in meeting his/her social and emotional needs, and (4) adequate psychiatric and medical services. Such needs can be addressed by staff with adequate knowledge of autism, and of teaching methods demonstrated to be effective with this population.

Objectives

The present proposal has two main objectives:

1. To provide a quality, cost-effective service for adults with autism/PDD in our region that will:
 - guarantee immediate access,
 - accommodate the diversity of need (i.e., zero rejection rate),
 - assure the greatest independence possible, and
 - have the potential to serve larger numbers for their entire lifespan.

2. To maximize the viability of the service through:
 - the development of staff expertise in effective teaching methods,
 - parental/family involvement in all aspects of the service,
 - collaborative relationships with other agencies, and
 - regular evaluations of the effectiveness of the service.

Proposed "Hybrid" Model

The proposed service model developed out of (1) the commitment by WWAS and the associated local Waterloo and Wellington chapters of Autism Society Ontario to both direct and outreach services, (2) need surveys conducted in Waterloo-Wellington and province-wide, and (3) a process involving a day-long workshop (and several subsequent meetings) with professionals and families in the region. The model reflects local needs and resources, as well as the expertise and experience of diverse groups in the fields of autism and/or developmental handicap. A consensus was reached on the model of service most appropriate for our region (hereafter, the "hybrid" service model). The model encompasses direct day/vocational and residential services, specialized staff, ongoing collaboration with families, relevant professionals and other community agencies, and outreach and relief (see the accompanying diagram for a graphic representation).

Each component is outlined separately below, but all are conceptualized as essential and complementary parts of the entire service (to

be described in greater detail later). For example, adults with autism require day/vocational programs, not merely a place of residence. By the same token, consultation with families, other agencies and professionals is more effective when the consultants have ongoing direct client contact. Our intent is to provide, support, co-ordinate and evaluate services in the most effective ways.

Day/vocational programs

WWAS will provide direct service in the form of day programs in vocational training and work placement. Consistent with our commitment to the greatest independence possible, the day/vocational programs will focus on the development of job-specific skills, including relevant communication and social skills. The intent is to find various forms of paid employment (both full- and part-time), through negotiations with local companies/businesses. Clients will receive extensive on-site job training/coaching by staff specialized in teaching and managing people with autism/PDD. To assure that vocational training is given priority, the day program will function independently of the proposed residential service (i.e., staff complement will differ), and may serve adults with autism living with their families, or in any community residence.

The proposed day/vocational program is modelled on the widely acclaimed specialized service developed in Maryland (Community Services for Autistic Adults and Children; CSAAC, 1988). Over a period of approximately 10 years, CSAAC have successfully placed 70 adults with autism (including several "low-functioners") in meaningful paid employment, with varying degrees of ongoing support. This model of service requires a major commitment of staff time initially, but is offset by its remarkable success and long-term cost-effectiveness.

Residential programs

To accommodate the diversity and longevity of need, the proposed "hybrid" model will provide a variety of residential options. These range from semi-independent apartments or town houses, to more traditional group homes. Most of our adults with autism will require some form of round the clock supervision and assistance. However, CSAAC have shown that when employed during the day, significant numbers are capable of semi-independent living with minimal supervision (e.g., a total of 20-40 hrs. per week for 3 individuals). The proposed model will support semi-independent living, with varying degrees of supervision, whenever possible.

Our model will also interface with local community services, through the development of strategically placed group homes for adults with autism/PDD. These will be negotiated and launched by WWAS, and then managed either by existing agencies or by WWAS. In either event, WWAS will retain legal responsibility for the property, and will support and evaluate all such residential programs. Clients residing in these group homes will participate in the WWAS day/vocational program, thereby eliminating the need for residential staff during the day.

Finally, a WWAS "base" will be developed at some central location (probably "rural"), to include more integrated residential, day/vocational and leisure/recreational programs for the most severely and multiply impaired individuals, and for those who show particular aptitude for farm and outdoor work. This service will have the potential to accommodate Waterloo-Wellington adults with autism/PDD who remain in provincial institutions (43% of the 61 identified are in Oxford or Mid-Western Regional Centres). Collaborative and evaluative services, as well as outreach and relief, will operate out of the central WWAS "base".

Outreach and relief

In addition to the programs outlined above, community support in the proposed model will take the form of outreach services to any Waterloo-Wellington family or agency with an adult with autism. Outreach services will include collaborative development of individualized programs, "hands-on" assistance when required, and short-term relief and crisis management. The main goal is to support families and generic agencies in maintaining their adults with autism, by providing the necessary resources and training in all aspects of the disorder and its management.

Specialized staff

Staff will be selected for relevant qualifications and experience, for their potential as caring and innovative teachers/counsellors, and for their commitment to the philosophy of service espoused in this document. A comprehensive pretraining program will be provided to staff by local specialists in the fields of autism and/or developmental handicap. Pretraining will focus on the special needs of adults with autism, and will include the development of teaching techniques effective with this population, crisis management and standard safety procedures. Staff will, in addition, participate in regular, ongoing seminars, designed to keep them abreast of the latest developments in the field, and to share techniques/approaches demonstrated to be most effective in teaching and managing the behaviours

of adults with autism/PDD.

All staff (both day/vocational and residential) will be assigned primary responsibility for particular clients. As such, they will, in consultation with team members, assess their clients' strengths/weaknesses and interests, and develop and implement highly individualized programs designed to address clients' needs. In addition to their role as "front-line" workers, staff will assume a more indirect service role (e.g., negotiating with business/companies for paid employment, providing outreach to families with no service, or "hands-on" support to generic agency staff). This second role, designed to diversify staff responsibilities, will be negotiated, based on both programmatic needs of clients and staff interests and strengths. Staff will also be given the opportunity to lead particular programs and projects on a rotating basis with the consensus of fellow workers.

Our intent is to assure job satisfaction of staff, and to prevent the "burnout" and high staff turnover typical of services for challenging ("hard-to-serve") individuals. This will be accomplished by increasing the diversity of staff roles, by providing ongoing consultation with local professionals (notably, a language/communication pathologist and a behaviour therapist), and by increasing the profile and status of "front-line" workers. We also intend to reduce the number of administrative positions. A less hierarchical/bureaucratic service model could result in more competitive staff wages, while increasing cost-effectiveness relative to existing agencies.

Professional and parent members of the Board of Directors of WWAS will remain closely involved in their advisory and management roles with the planned services. They will also to plan for steady expansion of services in Waterloo-Wellington, as part of the WWAS ten-year plan (see diagram).

Evaluative services

Regular (yearly) comprehensive evaluations of all component programs (day/vocational, residential and outreach/relief) will be carried out by a research psychologist at York University. Program evaluation will include measures of the well-being and quality of life of individual clients served, as well as more objective outcome measures. In her position as Honorary Director of the WWAS service, this person will work closely with staff and consultants to the service, and will therefore be well informed about all aspects of each program.

Stages of Implementation

In the fall of 1991, the Ministry of Community and Social Services provided partial funds for Phase 1, the planning stage of WWAS's efforts to provide direct and indirect services to local adults with autism/PDD and their families. For that purpose, a senior planner-coordinator (James Perry) and later a second planner-coordinator (Karen Hillis) were hired. Phase 1 culminated in (1) the formal establishment of a WWAS Board, (2) a comprehensive needs survey (including data from local families and existing agencies), (3) the day-long service model planning session attended by local professionals and families, and (4) the drafting of the present proposal. We are now seeking operating funds for Phase 2, the initial implementation of direct services for adults with autism/PDD in Waterloo-Wellington. Capital funding for the homes has been approved by the Ministry of Housing as a high priority, conditional upon a commitment of operating funds from the Ministry of Community and Social Services.

Implementation of the proposed "hybrid" service model will be gradual, and will be consistent with our commitment to integrated and co-ordinated, direct and outreach services. We will begin in the first year by developing a specialized day/vocational program, and one urban group home, ideally in collaboration with an existing agency. The group home will accommodate 3-4 adults with autism (with one bed reserved for relief), and the day/vocational program as many as six individuals (4 plus 2 in stages). Whenever possible, clients will be placed immediately in a job in the community, and will receive the necessary training/coaching from WWAS staff to maximize success.

With demonstrated success, we will plan to expand the service during the second or third year of operation. At that time, the main priority will be to develop the WWAS integrated "base" service for more challenging individuals, including those who currently remain in Schedule 1 facilities. A needs survey will be repeated then to assure that expansion plans and programs take into account the most pressing needs of families.

Relevance and Originality

The proposed "hybrid" service model for people with autism/PDD in Waterloo-Wellington is original in several respects. First, it provides local expertise in the teaching and management of individuals who are now widely recognized as challenging or "hard to serve." The proposed service will interface with other community agencies, individual families and relevant professionals, providing the much needed assistance in addressing the multiple and complex needs of people with autism/PDD. The intent is to empower the Waterloo-Wellington community with the supports and

expertise necessary to provide effective and stable services to a population who historically have been denied access to community services.

Our vision of integrated, co-ordinated services, including direct, collaborative and outreach/relief services, is supported by the experience of successful programs for adults with autism/PDD developed elsewhere. The proposed model is innovative in several respects. The built-in flexibility and diversity is designed to assure service to larger numbers of adults with autism/PDD at all functional levels. Clients will be assisted through all transitions or adjustments they may experience throughout their entire lives. All programs will be developed to maximize success, and to allow clients to move, for example, from group homes to more semi-independent living quarters. The model meets local needs, as expressed in the stated objectives. The feasibility of our model is strengthened by (1) our commitment to staff job satisfaction, (2) the prior establishment of a good rapport with local families, agencies and professionals, (3) the competence and commitment of our Board of Directors, (4) our strong working relationship with both the MCSS area office and the Ministry of Housing, and (5) the firm foundation established by WWAS's Phase One.

Our goal is to support people with autism in attaining the greatest independence possible, a critical part of which depends on the person having a purpose, being productive and feeling valued/esteemed. We are confident that our service model will provide the necessary supports to more diverse and greater numbers of people with autism and related (severe) developmental disorders. The need for the proposed service in Waterloo-Wellington is urgent. Aging parents, many of whom have suffered significant strain for years, are understandably no longer able to cope. With intensive effort now, adults with autism/PDD can develop more independence in life and work skills, and thereby become less of a burden on society while enjoying a better quality of life.