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Oxford Regional Centre's Aging Population

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Background Report for the Seniors Planning Committee, ORC

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In March, 1984, Oxford Regional Centre's total population was approximately 640 developmentally handicapped residents, 270 of whom (42%) were over the age of 45. Of these, approximately 230 were over 50 years of age, and more than 50 were over 65. With continuing admission and demission trends operating during the Drea Five-Year Plan Facility Closure process, it was speculated that almost half of ORC's population would be classifiable as 'senior developmentally handicapped' by 1987.

In March of 1987, at the time of this writing, the total population of ORC is approximately 480, and approximately 240 (50%) of these residents are over age 45. The population over 50, from 230 (about 36%) in 1987, is now approximately 190 (42%). It appears that the predictions offered in "Oxford Regional Centre's Aging Population", March 1984, by Terry Kirkpatrick, Cathy Inglebrecht and Robin Pow, were relatively accurate. At that time, it was suggested that something be done about the 'seniors population' at ORC.

> "we are reminded urgently of the need for some form of planning for the ORC aging population by the magnitude of the numbers at present and the supportable claim that the proportion of seniors is in fact increasing...it is very easy to ignore, even for the time, the aging population. These individuals tend to demand fewer services for themselves, and less attention than the formerly described groups. It would indeed be a shame to see this growing group of elderly retarded individuals "lost" in the drive to adapt institutions to the changing requirements of overall services for the developmentally handicapped..." (p. 4-5)

> At the time of this report, the proposal was made that "ORC begin focussing attention more directly and more intensively on programs and services for the institutionalized aging population..." [since]...there is absolutely minimal community activity/development to meet the needs of the large group of elderly retarded persons living presently at ORC."

Other facts have been gathered since that time, which gives us a bit of a "picture" of what has been happening since the 1984 report. In general, neither ORC's senior administrative group nor the various community advocacy groups and planning bodies have shown great strides in completing any overall plans for services to seniors with developmental handicaps. In late 1986 however, ORC's management set forth a task group to report on some general principles for planning for seniors at ORC. This committee, chaired by Ivy Scott, set out to gather specific information regarding placement of seniors, including existing services, capacity for expansion and willingness to include ORC residents in such

expansion; current needs and characteristics of seniors residing at ORC, as well as basic suggestions about services required currently and not received; program requirements for serving seniors in the community as seen by existing services and staff at ORC whose interest lies in services to seniors; and finally, to produce a database for planning information on seniors presently at ORC. "Seniors" are defined arbitrarily for these planning purposes as people over 45.

At the time of this writing, the job is almost completed. The database is up and running, with more information to be added on some residents as it becomes available. Most of the "facts" are in. These facts include:

1. Demission "failures" or placement "breakdowns" for seniors are approximately double (24% compared to 14%) that of other age groups, computed over the last six years (since 1980). This is despite the "seniors" age group's relatively higher intellectual and life skill functioning levels, and the relatively lower incidence of personality disturbance and behaviour disorders perceived in this group. It is noteworthy that a large number of seniors have had placement opportunities offered to them in the last five years (approximately 30), primarily in the Family Home Programs run by ORC, Midwestern Regional Centre and the Wellington County Family and Children's Services.

2. the finding that 16% of all admissions over the last five years have been of people 50 years and over; most of these, apparently attributable to START Centre placement failures.

3. the great bulk of placements of seniors in the last five years have been to the Family Home Program operated by ORC, with a few others to the Family Home Program operated by Midwestern Regional Centre (MRC) in Palmerston, and the Family Home Program operated by the Wellington County Family and Children's Services in Guelph. To the best of our knowledge, fewer than 5 individuals have been placed in group homes or residences operated by local Associations for the Mentally Retarded. The long term stability and service quality of the Family Home Programs has not been evaluated, nor have they been operating long enough to have estalished a "track record". The fact that two of the three programs are operated by facilities suggests "failures" would likely result in a tendency to re-institutionalize elderly residents for health as well as behaviour control reasons. It is also noteworthy that the greater proportion of the high "failure" rate for seniors is attributable to Family Home placements.

4. a survey of Community Agencies and Services in the three MCSS Areas surrounding ORC (Hamilton, London and Waterloo), carried out by the Seniors Planning Committee of ORC, suggested that most Associations and Home Operators serve a small number of seniors in each geographical area. Most of these programs are not planning expansions specifically for seniors, and, indeed, tend to indicate concern for the aging populations currently in their own

jurisdiction. That is, many are not sure what they will do with the aging clients of their Association or Agency currently receiving services. The Metropolitan Toronto Association for the Mentally Retarded, Task Force on Aging, suggested in a 1984 report that

"Rather than create a new and small service speciality, it might be advisable...[to] work towards ensuring equal access for the people it serves to those services now available or available in the future to senior citizens in general in the light of individual circumstances and health." (p.6)

Unfortunately, services to seniors in general are not frequently being made available to those with developmental handicaps, and, when retarded seniors do enter such services, problems are frequently encountered. It is not at all unusual to find retarded seniors physically and socially segregated from the remainder of the home's population in nursing homes, homes for the aged, and retirement or rest homes. All of this is to say nothing of the quality of life for seniors in general in many such homes. It is probably fair to say that the quality of life for most seniors at ORC, whether measured in terms of social, recreational, health, occupational, material or autonomous well-being, is better than the bulk of retarded seniors currently in seniors accommodations in the community.

5. Referrals to the Family Home Programs, especially that of ORC, have slowed significantly due to difficulties finding suitable homes for seniors specifically and increased caution due to operational problems in the program and precedent from a number of failures. Placements of seniors to all other types of program are generally not being considered at this time. Nursing Homes, Rest Homes, Homes for Special Care and Homes for the Aged, because MCSS has placed a "moratorium" of sorts on these types of placements. Group Home (AMR) placements have generally slowed considerably, due to perceived quality problems with some service agencies who are expanding, reluctance to undergo further expansion among high quality agencies over-extended during the most recent facility closure process, difficulty finding day programs suitable for seniors, and a general unwillingness to consider seniors for placement in many agencies, especially when younger residents are applying for the same vacancy.

6. Internally at ORC, despite the expansion of residential services designated for seniors, (every unit of the Centre now has one whole residence for seniors), and the generally flexible day program offerings of a good Program Services Department and Vocational Department, there is a perceived inadequacy in accessing appropriate material and programming services designed primarily for seniors. This is especially true of adapted equipment, but also support services for seniors in general is perceived as weak. Such important issues as comfort allowances for non-working seniors; more frequent social and recreational services for seniors; better procuring and maintaining of volunteers, who, for seniors with little family involvement or advocacy, may have nobody involved with them who is not paid to do so; more available transportation, which, for seniors, may allow

them their only 'escape' from the constant tedium of ward life; special consultation from professionals well versed in services and programs for elderly people, especially in tailoring social programs for individuals with high health-related needs; more available and easily accessible prosthetic devices, and physical modifications to environments to make them more accessible and usable for seniors, especially seniors with mobility handicaps; advocacy; staff with special psycho-geriatric skills and knowledge, especially for psychotherapeutic and rehabilitative work with physically impaired seniors; religious involvement, and care for the seniors' concerns over illness and death. Many facilitative suggestions for development of such services and programs for seniors were made in the paper by Kirkpatrick et al. in 1984 (esp. see pp. 8-16). However, without administrative support (policy support, technical support, financial support) and a mandate for development of seniors programs and services, little development has occurred in the intervening three years despite great individual efforts by a number of interested and involved front-line staff and some managers.

From this information, a number of reconceptualizations of the 'seniors' problem were required (i.e. discharge planning, converting of ORC settings over to exclusive services for 'seniors', development of 'psycho-geriatric' competence, etc.).

The summary of these reconceptualizations will be included in the ORC Seniors Planning Committee report, which will be available shortly after this report is available. However, it seems appropriate to once again re-iterate the recommendations made in the 1984 report by Kirkpatrick et al. (notes in square brackets were added for this report):

1. That first and foremost, a working group of highly committed personnel, representing administration, consulting services, counselling, health services, and support services, be struck. [It is important that this group have complete administrative support. The current seniors planning group does not have either a clear mandate (purpose) from administration, nor representation from administration.]

2. That the purpose of this working group be to produce a concrete, working document for the mounting and coninuation of exemplary, cost-efficient programs for the aging and elderly population at ORC. [Note that the site for such programs need not be ORC. In the absence of any other such interested planning group, seniors will have to be planned for by ORC, and if no other options are to become available, will have to be served by ORC as well.]

3. That this working group planning for the elderly developmentally handicapped individual make the following considerations [in principle] in their development of a concrete plan for programs and services:
   a. that services, wherever possible, be provided in the most satisfying venue for elderly developmentally handicapped clients,

as determined by further research with the clients themselves, present community service providers who might offer such services, and funding bodies.
b. that locations for accommodation be integrated as close[ly] as possible, physically, to the bulk of activities and services provided for the elderly population as a whole in the local community. [Where dictated by client preferences, closeness to other desired and desirable communities (including ORC) should also be considered.]
c. that locations for such accommodation be easily physically accessible to a variety of mobility aids, including walkers, wheelchairs, canes etc.
d. that locations chosen for the presently fit and independent elderly developmentally handicapped person have the capacity to adapt to the inevitable deterioration in these dimensions with increasing age, or have smooth access to appropriate and compatible forms of accommodation and service which can serve the needs of the more severely disabled individual.
e. that such services have available to them, a variety of day and evening activity programs which serve social, therepeutic, habilitative, and motivational needs of the elderly developmentally handicapped person.
f. that such services have available to them, a variety and abundance of transportation methods in order to offer a high degree of independent access as well as easy access to programs and activities outside of the residence in which the individual lives.
g. that such services have available to them, a "referral out" mechanism allowing individuals to transfer, [if desired], to other facilities, programs and day programs for example.
h. that such services have available to them, adequate staffing in order to provide a variety and abundance of interesting and stimulating activities and programs.
i. that such services, both in the planning stages, and those already in existence, be evaluated regularly with the criteria included in this report as a basis, prior to implementation or in order to justify continuing support.

At this time I would also add the following:
1. Reference should be made to the following documents, relating to problems in the quality of service provision for residents at ORC, since they relate to the quality of service provision for seniors especially:
a. A.T.R.U. Social Change: Draft Report - T. Kirkpatrick, J. Blonde and S. Stere. Suggested major challenges in meeting psycho-social needs of residents, requiring comprehensive attention by a multi- or trans-disciplinary team of direct-care staff and necessitating combinations of behavioural, cognitive, dynamic, ecological, and educational interventions, in conjunction with medical/pharmacological assistance; and that these were rarely being addressed. Furthermore, suggested joint community-facility planning and/or modifications of programs committed to de-population of facilities.
b. Report of the IPP Revision Subcommittee, 1984. T. Kirkpatrick,

chairman. Suggested major deficiencies in the general framework for assessment of need and planning of services for residents at ORC, with recommendations for numerous revisions to the entire fabric of the current Program Planning system in use at ORC. Of particular relevance to seniors were a number of proposals designed to reduce the frequency of planning, and the over-representation of educational and behaviour-modification programs designed to change the individual, with a new emphasis on changing the ecology and other non-client environmental influences on lifestyle (such as tolerance, opportunities for non-contingent activities, etc.).

c. Aging and Elderly People with Mental Retardation, Stan Delaney (OAMR). Presented at the "Enhancing Quality of Life" Conference in Toronto, June 25 and 26, 1984. Details surveys of senior developmentally handicapped people living in the community, across Ontario, as well as relevant information about the elderly handicapped population in general culled from the literature on the subject.

d. Mandate for Quality, Volume II Missing the Mark: An Analysis of the Ontario Government's Five Year Plan. McWhorter and Kappel (NIMR) Documents failure of the "machinery of the Ontario system" (p. 25) to work:

> "Major and necessary components had never been implemented, including a) case management and contracting mechanisms which make planning, development and resource use efficient. b) quality control, and c) focussed advocacy. Program accountability and feedback mechanisms had never been operational to begin with, and this may account for the fact that the actual state of the organization was not accurately appreciated by those who proposed, approved and supported the "Five Year Plan" in the first place....Time has gone by and the ministry has not acted to develop the management capabilities essential to the responsible exercise of its mandate...The elements needed for community service systems to develop and operate are hardly trade secrets. The knowledge base is available and to a large extent reflected in the ministry's own publications. Very few of the elements, however, have been implemented anywhere in Ontario..." p. 25

e. Oxford Then and Now: A Report on ORC's Client Services 1980 to Present. T. Kirkpatrick 1987. Documents client care concerns from ORC staff and outside representatives (parents, community agency staff, other professionals in contact with ORC, etc.) which have been largely unaddressed since 1980, despite numerous cases where the issues have been brought to ORC management's attention and alternatives suggested which have not been responded to. Particularly admissions, accountability, planning, equipment for residents, comfort allowances, slow response to requests from front-line staff on behalf of residents, etc.

In summary, this background report documents serious problems directly relating to seniors which have been largely unaddressed by the "System", where management of MCSS at ORC and upward into Regional and Ministerial levels has been largely unresponsive to the special client care concerns and issues brought to them by front-

line staff, in general. Although names can certainly be named, it is the pervasive attitude of "laissez faire" in MCSS as a whole which must be confronted as the greatest "stumbling block" to planning and implementing quality services for seniors, either at ORC or in community programs, at the present time. If we at ORC cannot resolve our own current problems with providing these quality programs, we cannot begin to expect such quality and initiative in the community. As a result, the fundamental need for approaching the goal of building a better world for developmentally handicapped seniors, is management committment and continuing support at all levels of planning and implementation. For ORC to do this, will require a pro-active rather than reactive stance; good personnel management; promotion of competence over longevity; a dynamic leadership at all levels of the hierarchy; and real committment, not only from front-line staff, but also from administrative levels, to solve problems and be involved in the development of new services; that is, to become "part of the team". The challenge is again issued, as it was three years ago. Hopefully, someone is listening this time.