
REVIEW OF
CHILDREN'S TRAINING CENTRES
IN NOVA SCOTIA

A Report and Recommendations
to the Minister of Community Services

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REVIEW OF CHILDREN'S TRAINING CENTRES IN NOVA SCOTIA

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REVIEW OF CHILDREN'S TRAINING CENTRES IN NOVA SCOTIA

Background

Four Children's Training Centres (CTCs) were established in Nova Scotia in 1969. A major role of these centres was expressed as follows - "The goal of the Children's Training Centre is to have the children learn basic life skills such as feeding, dressing, and toilet training so they can eventually return to their homes or non-institutional settings." Optimally, children with moderate to severe mental handicaps were to receive training and instruction that was not available in their home communities. The Committee notes that, before the closure of the Pictou and the Digby CTCs, nearly all persons who left these facilities went to Adult Residential Centers. It must be concluded, therefore, that the major goal cited for CTCs was not being realized. In fact, many of the children admitted to the CTC, had severe to profound handicaps which precluded their achieving the stated goal of returning to their natural homes. The support system in place at that time simply did not empower their parents to repatriate their children.

The Sydney CTC eventually expanded to include a nursing unit for children who had both profound mental handicap and serious medical problems. These children were deemed to require continuous nursing care.

Attitudes towards institutional care changed over time and admissions to the CTCs decreased. In 1991, the Provincial Government announced plans to close the CTCs. By 1993, the CTCs in Pictou and Digby were closed and most residents were placed in small option group homes. A few residents were transferred to the CTC in Dartmouth, or placed in foster homes or Adult Residential Centers.

In the spring of 1993, there was one allegation of sexual abuse and several allegations of physical abuse at the Dartmouth CTC. As a result, three children were withdrawn from the facility by their parents. Programs at the Dartmouth CTC then came under intense scrutiny by the Department of Community Services. Staffing levels were dramatically increased and programming underwent major changes. A staff person was seconded from the Staff Training Unit of the Department of Community Services to assist in programming. It must be noted that during the time of this review, staffing levels at the Dartmouth CTC have been reduced several times (although not to a level as low as before the enhancement). There has never been a significant change in the Sydney CTC staffing level.

The CTC Review Committee was appointed by the Minister of Community Services to examine the operations of the Dartmouth and Sydney CTCs. The Roeher Institute was selected by the Minister to provide consultative advice to the Committee. The Terms of Reference assigned to the Committee are found on page 4 of this report. The Committee began its work in February 1994 and completed the Review in September 1994. The Committee's essential task was to review the current functioning of the CTCs and the options for community placement of residents in the course of pending closures. Recommendations were to be guided by those quality of life indicators which might apply for CTC residents. The Roeher Institute staff met with the Committee several times over the course of the review and prepared a background report which is attached as Appendix "D". The report is put into context by a brief critique, attached as Appendix "C".

In December 1993, the Minister's Advisory Committee on Services to Children with a Mental Handicap presented a comprehensive report. Many of their recommendations, dealt with the closure of institutions. The CTC Review Committee was appointed shortly after the Advisory Committee's recommendations were accepted by the Minister of

Community Services. The Minister subsequently announced that the Dartmouth CTC would close in 1997 and the Sydney CTC at a later, unspecified date. The future of the Nursing Unit at the Sydney CTC is uncertain.

The Review Committee is well aware of the current economic climate in Nova Scotia and current efforts to reduce the overall budget of the Provincial Government. From this perspective, we have attempted to make responsible recommendations while not allowing projected cost to interfere with our vision of a desirable quality of life for CTC residents.

Admission to a CTC may well reflect an imbalance between a family's ability to provide home care for a severely handicapped child and the community's ability to support them in the endeavour. The Committee was impressed by the degree of involvement that most families continue to have with their institutionalized children.

The Committee was also struck by the level of commitment which the staff of both CTCs exhibited in their care and concern for the residents.

Throughout the review and this report, the Committee frequently refers to all residents as children. Many of these young people are over 18 years of age. Referring to them as "children" is not reflective of a lack of respect but rather an acknowledgment of their level of dependency and resultant need for thoughtful, compassionate supervision.

TERMS OF REFERENCE

Purpose:

The objective of this Review is to assess the current standard and level of operation of all aspects of the Children's Training Centres (CTC's) and to make recommendations for change and all options for care which will result in improved quality of life for residents. Future direction for residents will be evaluated consistent with Government's public statements regarding the provision of services to mentally disabled and handicapped persons.

Time Frame and Reporting:

The Review will be completed over a three-month period beginning in September, 1993. At the end of that period, the Review Committee will submit a Report and Recommendations to the Minister of Community Services.

1. **To examine the current philosophy of operation for the centres and the administrative structure under which they operate by undertaking:**
 - a review of the Administrative and reporting structure for the Centres within the Department of Community Services.
 - an examination of the administrative and reporting structure within each of the CTCs with specific focus on the flow of communications at all levels and across levels of staff.

- a review of administrative procedures for incident reports including form, content and follow-up.

2. To assess the non-program specific operation of the Centres by reviewing the following:

- the educational and employment requirements for staff in all operational areas and the process/procedures related to hiring.
- the current configuration and qualifications of staff in each operational area.
- the current ratio of counsellors to children by shift, use and frequency of use of casual staff in each operational area, responsibility for staff scheduling, the frequency and nature of such items as injuries and grievances and the way in which they are handled.
- the frequency and use of in-service training or other methods to increase and update the knowledge and skills of staff in each operational area.
- Access to medical services provided at the Centres:
 - the role of the physician
 - on-site and frequency of visits
 - use of specialists
 - frequency and cause of emergency treatments
 - protocols in place for responding to an emergency, etc.
 - medical management in terms of procedures and protocols for medications use and administration

- assess the frequency and type of injuries incurred by children and staff and the process, procedures and services used to respond.

3. To examine and create a profile of the clientele the Centres now serve and those for whom service is currently being requested by reviewing the following:

- the children currently residing on a permanent basis in each Centre by age, functional level, age at admission, referral source, behaviour case requirements, diagnosis where there is one exceptional or special need beyond that "normally" provided by the CTCs. Comment should be made on the appropriateness of the placement.
- the frequency and use of respite care in each Centre over the past year:
 - for who it is being used, how often, for what purpose
 - effect of respite care usage on staff and children who are permanent residents of the CTCs.

4. To assess the program of each Centre including, but not limited to, the following:

- a review of the overall weekly routine for each Centre.
- an examination of the development, extent and use of Individual Program Planning and/or Individual Educational Programs for each child

- who develops the program(s)?
 - who is responsible for carrying through with the program(s)?
 - who supervises the program(s)?
 - how often is the program(s) updated?
 - is there documentation on individual files validating the above?
- a review of leisure and recreational programming both within the institution and in relation to the use of community schools
 - a review of educational programming, both on-site and external to the facility
 - a review of the use of external specialists - e.g., psychiatrists, psychologists- for consultation and/or treatment purposes in relation to programs and/or care provided to the children
 - a review of any special or exceptional programming provided.
- 5. To review and assess the relationship of the CTCs with parents/guardians and the community including:**
- the communications structure and flow between parents/guardians and the Centres
 - review the role of parents/guardians in the placement and on-going care of their children
 - wardship issues

- the use of community school placements
 - *the frequency of use of community facilities, other than schools.*
6. In the case of the Sydney CTC, particular note should be taken of the children who are receiving care in the Nursing Care Unit. A through examination of the operation of that Unit, including staffing and clientele, should be included in line with these Terms of Reference.

Methods for the Review

The Committee gathered information in a variety of ways. These included:

- multiple visits to the Dartmouth and Sydney CTCs;
- direct observation of the residents and their programs;
- interviews with the Superintendents and Assistant Superintendents of both facilities;
- interviews with senior "head office" staff
- interviews with senior counsellors, teachers and "line staff" of both facilities;
- interview with the contracted physician in Sydney;
- interview with the consulting psychologist in Dartmouth;
- interview with a Department of Community Services' In-Home Support Worker;
- reviews of administrative and resident records and policy manuals at both CTCs;
- school visits and interviews with teachers and senior school board personnel in Sydney and Dartmouth;
- three meetings with parents of CTC residents in Sydney;
- two meetings with parents of CTC residents in Dartmouth;
- two individual meetings with parents of former CTC residents in families who had withdrawn their children while alleging abuse at the CTC;
- an individual meeting with the family of a young female resident of the Dartmouth CTC;
- a meeting with the Family Support Network of Nova Scotia;
- interviews with a sample of social workers responsible for children in care;
- interview with the Supervisor of the Child Abuse Registry;
- visits to an Adult Residential facility (Braemar) and a Home for Special Care (Evergreen);
- visit to small option group home (Lower Sackville);

- consultation with Ross Dawson, Managing Director of the Institute for the Prevention of Child Abuse in Ontario;
- review of the taped transcripts from the trial of a staff person charged with physical abuse and later acquitted;
- review of the financial audit of the Dartmouth CTC;
- review of the reports of abuse allegations and findings;
- review of literature and telephone interviews with respect to de-institutionalization practices, funding arrangements, and service models in other provinces;
- review of literature about quality of life for handicapped persons;
- interviews with parents of children who have been returned to the community from the Pictou, Dartmouth and Digby CTCs; (the survey results, carried out by Elizabeth Burt BA, are attached as Appendix B)
- discussions with the Roeher consultants;

The terms of reference for the review called for a "client profile". The Committee visited the CTCs and observed the functional levels of the residents first hand. Additionally, the California Adaptive Behaviour Scale was completed for each resident and a summary profile was developed.

No validated instrument for measuring "quality of life" for mentally handicapped young people was known to the Committee or to the consultants; therefore, the review was based on a number of principles which are subjective and, therefore, value laden.

The Committee believes that residents of the CTCs should have a life marked by equality with other citizens, equity in accessing opportunities and dignity of person. Central to these principles, is the concept that decisions for these inherently dependent individuals must be made in their best interest. These principles were held by the

Committee as inviolate and are consistent with the Report of the Minister's Advisory Committee on Services to Children with a Mental Handicap.

Overview of Areas of Concern:

The review had two major areas of concentration. Day to day programming and life at the CTCs were considered first. Additionally, the issues related to community placement for residents were reviewed. These two areas of concentration generated fifteen areas of concern. Specific recommendations for each of these areas were developed and are listed below. There were three themes which had an impact upon several of the areas of concern. These included issues related to the **SAFETY and SECURITY** of the residents, the need for better **COMMUNICATION** and both administrative and programming **CONSISTENCY**, as well as the unique issues associated with the Nursing Unit in Sydney. These three areas are discussed separately.

MAJOR AREAS OF CONCERN

1. Safety and Security

Parents of residents currently in the CTCs are very concerned with long term safety and security issues. Parents repeatedly reported that they felt their children are safe in their current placements. The crisis of the spring of 1993 has not undermined the confidence of the parents who have kept their children in the CTCs. They are more concerned about safety in the future, should their children be placed in the community in different residential arrangements. They point out that staff in small option homes may not be as well supervised by peers, simply as a result of smaller numbers. There are often high rates of staff turnover in such settings and it was noted that the income of workers in small option homes will likely be considerably less than at the CTCs. There are presently no provincial standards for small option homes.

Long term security is a key issue in parental attitudes toward change. Placement in the CTCs has not been means tested and, once achieved, has seemed secure. The Provincial Government's commitment to these young people when they reach the age of 18 years or when community placement is attempted has never been specifically articulated and this has been a source of parental anxiety. Given that many of the residents at the CTCs are already over age eighteen years, the level of life-long government support for these individuals must be unambiguously guaranteed; otherwise, arrangements such as small option homes will be viewed by parents as potentially temporary and always vulnerable to future budget cuts.

The Committee Recommends:

- 1.1 That standards for small option homes be developed by the Department of Community Services. These should include mandatory criteria for preservice training, ongoing staff development programs and the use of a personality profile instrument in staff selection. A routine, enforced system of inspection by the Department of Community Services, to ensure compliance with standards, is needed.
- 1.2 That the nature of Government's long term commitment for support of individuals currently in the CTCs be developed and articulated.

2. Communication and Consistency

In the Committee's opinion, the impact of the crisis of the spring of 1993 at the Dartmouth CTC could, in part, be blamed on management style. The parents who alleged abuse of their children repeatedly noted inconsistent, inaccurate or inadequate communication with the CTC administration and staff. Not all parents of children in the CTC had the same concerns; however, the parents who chose to remove their children consistently reported poor communication from management. The Committee reviewed letters which directed parents as to with whom they might discuss specific issues. These letters seemed particularly inappropriate. Management also appeared to have difficulty understanding and incorporating parental concerns and wishes into residents' activities and programs.

The Dartmouth CTC's response to the allegation of sexual abuse did not follow accepted or mandated procedures and an initial denial of the possibility did more to escalate the crisis than to resolve it. The current protocol for dealing with suspected sexual or physical abuse charges the Superintendent with the decision as to whether or not the concern is legitimate, prior to the formal reporting of possible abuse. The Superintendent is to "determine if there is credible information on which to make a report to an agency...". This discretionary power

homes scattered throughout the province than it would be to do the same in a centralized facility.

There continues to be suspicion (and some confirming evidence) that some children have had access to higher levels of government support, simply because their parents were better informed or lobbied more effectively. Details of all available services and potential arrangements have not been universally shared with parents of CTC residents.

The CTC administrative system has no specific formal process for dealing with parent complaints or concerns. While many parents indicated that they felt comfortable discussing concerns with the Superintendents of the CTCs, others stated that they did not.

The Committee Recommends:

- 2.1 That parent representatives participate in regular meetings with the Division Administrator and that the results of these meetings form a part of the regular evaluation of CTC administrators.
- 2.2 That management style, especially as reflected by communication with parents, be monitored by senior Department of Community Services officials and corrected as required.
- 2.3 That staff and administrators in the CTCs adhere to the requirements for reporting suspected child abuse as outlined by the Mandatory Reporting legislation and Departmental protocol.
- 2.4 That future investigations of suspected abuse be independent of anyone involved in the management of the CTCs.
- 2.5 That parent support groups be fostered at the CTCs and plans be encouraged for an ongoing parent network after the CTCs are closed. Such a group could ensure that all the children are receiving the best available services.

- 2.6 That announcements by the Department of Community Services or other government agencies that have a major impact on the CTCs be delivered to parents or guardians of residents of the CTCs before being made public.
- 2.7 That a formal process dealing with parent's concerns and complaints be created and publicized.

3. The Nursing Unit at the Sydney CTC

The Committee spent considerable time becoming familiar with this special group of children. They were, by far, the most seriously handicapped of all the children in the CTCs, although similar to the child population observed at the Evergreen Home for Special Care in Kings County.

Characteristics of this group included:

- all but two are tube fed and have significant swallowing difficulties
- several require frequent oral suctioning;
- all have severe motor deficits;
- most have severe epilepsy;
- some experience episodes of apnea;
- social interaction is very limited

Statistically, these individuals have a significantly reduced life expectancy. Unfortunately, one child died during the time of the review.

The Committee's opinion is that they are unlikely candidates for a return to their natural homes or for associate family placements. They will continue to require frequent nursing care. While small option home placement would be possible for these residents, it would require very special staff with considerable extra training, similar to the exemplary staff presently in place through an arrangement with the

Cape Breton Regional Hospital. The cost of such arrangements is predictably very high, especially if nursing services were to be delivered at multiple sites. While it is difficult to specify exactly how an altered placement would improve the quality of life for these children, there is, nonetheless, no particular reason to maintain these children in their exact current placement. They could be properly cared for in a different setting. The Committee researched the arrangements for similar children in other jurisdictions and were struck by some of the high quality community options being utilized in British Columbia. It also noted that the staff at Evergreen Home for Special Care were able to access community activities much more frequently than did the Sydney Nursing Unit. Trips to Halifax for swimming, forays into the local community, parks and amusement facilities, camping and visits to the homes of staff were all carried out regularly. The non-medical orientation of the Program Director and the suitability of the vehicle available were considered to be contributing factors and these conditions could be replicated in Sydney.

Possible alternatives to the existing model of service include but are not necessarily limited to:

- two adjacent/attached small option homes (duplex style) with shared nursing staff;
- a single group home for all seven children with nursing care and staffing at the same level they presently receive in the Nursing Unit.

Although these children have virtually grown up in an institutional setting, their care is not so complex as to warrant hospital placement. The Committee **adamantly** believes that they would be inappropriately placed in a large adult institution. Their extreme dependency demands and deserves the protective nature of a small, children's facility.

The Committee Recommends:

- 3.1 That the provision of 24 hour nursing care continue for the children in the Nursing Unit. The contractual arrangement presently in place appears to be excellent.
- 3.2 That a parent of a child in the Nursing Unit and a representative of the Department of Community Services visit other service options for the "medically fragile" elsewhere in Canada to gain a first hand view of different ways of providing appropriate care for these children.
- 3.3 That consideration be given to placing all 7 children in one or two special group homes, thus retaining the identity of the unit and the integrity of the level of care while providing a more community style setting.
- 3.4 That placement of these children in an large institution or hospital not be considered as an option.
- 3.5 That, wherever the residential placement, more attention be given to community participation. Programming should be a non-medical responsibility assigned to a Program Coordinator and transportation suitable to the population should be available.

SPECIFIC ISSUES

1. General Care

In assessing the level of general care in the two facilities, the Committee made a number of observations over the course of their visits.

Both CTCs are extremely clean. There was a consistently high level of general housekeeping. Residents were observed to be clean and appropriately attired - in the sense that children were not seen semi-clad or in apparel unsuited to either the temperature or their activities. We must note, however, that some parent's comments reflected considerable concern. Children wearing other residents' clothing, clothing items and other possessions being lost, and residents going out of the CTC inappropriately attired are all issues. The Review Committee sees the reported examples as being individually insignificant but collectively reflective of a broader issue the depersonalization of the individual resident.

Similarly, while the obvious efforts to personalize the dormitory areas of the CTCs are laudable, the fact remains that a large area with six to eight beds does not compare to a bedroom in a single family home and cannot be as personal and private. The lack of curtains in some rooms of the Dartmouth CTC underscored the institutional nature of that facility.

An exception worthy of note was the bedroom that the Sydney CTC staff outfitted for two of their older residents. Attractive and highly personalized by family pictures and other memorabilia, it was reminiscent of a well appointed college dorm room - if not quite the bedroom which might be found at home.

The Committee did not observe any inappropriate disciplinary actions or interactions, nor did they hear staff at either CTC speak to or about any resident in a disrespectful or demeaning manner. No resident was observed to be fearful of either staff or other residents.

The arm restraints being used with one resident raised questions as to (a) his suitability for being a resident of the CTC; and (b) the level of consultative support and staff training being provided at the CTCs to equip personnel to either deal with aggressive behaviours in the short term or to effect positive change in such behaviours over the long term. One situation observed in the Sydney CTC raised a concern as to whether a somewhat diminutive staff person and a CTC resident were at some risk when a second resident became agitated and aggressive and no backup staff person was at hand.

Injuries to both staff and residents occur at both facilities. Unlike injuries to residents, which are scrupulously recorded, staff injuries in Sydney are rarely documented. In examining the incident reports in Dartmouth, the inverse relationship between staffing levels and injury reports was clear. When staff was significantly increased in 1993, injuries to both staff and residents declined dramatically. Parents expressed some concern that the more passive residents were put at risk of injury by those more aggressive when there were inadequate levels of staff.

The level of privacy afforded the residents was variable; an example being that toilet cubicles in the Dartmouth facility had no doors while those in Sydney did. It was also noted that, in one instance, privacy curtains were drawn when a resident was being changed while, in another, the person being changed was clearly visible from the hallway.

Both staff and parents reported that residents in the Dartmouth facility were regularly strapped onto a toilet seat and left unattended for periods of time. The Committee believes that this practice is both an affront to the dignity of the individual and a serious safety issue.

Institutional life limits choices because of regimented routines that are established in order to "get things done" in an efficient and orderly manner. Residents have few choices in their daily attire, foods for meals and snacks, or in selecting preferred activities. There is no real opportunity for residents to have a say in the operation of the facility. We recognize the difficulty of providing more opportunities for choosing and decision making to the residents - both as a function of the organizational structure of the facility and of their natural limitations; however, this aspect of the program must be developed or strengthened, preparatory to moving out into the community.

The Committee Recommends:

- 1.1 That policies of the CTCs reflect principles of dignity and individualization and that specific practices contradicting these principles be prohibited. Examples include washrooms without doors, residents wearing the clothing of other residents, and strapping residents to toilet seats.
- 1.2 Given that the CTCs will close and that most residents will be living in community residences, programming which develops opportunities for choice and decision making needs to be undertaken.

2. Health Care

Each CTC has a contractual arrangement with a family physician for the general medical care of residents. Medical care seemed promptly available. The relationship among the CTC, parents and physician in Sydney appears exemplary. Parents of children at the Dartmouth CTC described very little direct contact with the physician; however, he is available to the CTC for all health care concerns. Neurology services, especially for children with epilepsy, are available on a consultation basis. Other pediatric services appear to be easily available to both CTCs.

Annual physical examinations of residents have usually taken place. Management of behaviour altering drugs has generally been by the CTC's own physician.

The system for dispensing medications is well designed in both CTCs with little chance for errors.

The medical manual for the CTCs does not indicate the date of last changes or updates. Authorship of individual sections is not noted.

Dental services appear adequate for the two CTCs. Physiotherapy and occupational therapy services are less available.

The Committee Recommends:

- 2.1 That a single physician for the entire institution is preferable even though the choice of a personal physician for each child may seem attractive.
- 2.2 That genital examination be a documented part of the annual physical examination.

- 2.3 That the use of behaviour and mood altering medication be reviewed on a regular basis by the physician, staff and where appropriate, a consultant. Such medication should require a reorder at least every six months, accompanied by a notation indicating the reason for continuance.
- 2.4 That the resuscitation status be clarified for each child in the nursing unit in Sydney and for all other residents with medical problems that have the potential for sudden deterioration (e.g. severe epilepsy).
- 2.5 That consulting physicians be encouraged to see the children at the CTCs, rather than have the children brought to offices and clinics. This should allow greater input from the CTC staff. Parents should be encouraged to attend these consultations but a staff member who knows the child well should always be in attendance.
- 2.6 That some medical appointments take place in doctors' offices in the community to foster integration.
- 2.7 That the First Aid and Medical Manuals for both CTCs be reviewed, updated, and signed by the author. Several sections are outdated (e.g. the sections on epilepsy, fever, chickenpox, oral rehydration).
- 2.8 That physiotherapy and occupational therapy services be contracted as required by the I.P.P.'s of the residents.

3. **Potential for Physical and Sexual Abuse**

The Committee was not mandated to determine whether sexual or physical abuse had actually occurred at the Dartmouth or Sydney CTCs. Our consideration was confined to the question of whether there were sufficient safeguards to minimize the likelihood of such abuse.

The Committee met with Mr. Ross Dawson, Managing Director for the Institute for the Prevention of Child Abuse. We are thankful for his willingness to share his expertise on the topic of abuse. The policies for investigating and reporting child abuse at the CTCs were reviewed and the Supervisor of the Child Abuse Registry was interviewed. It was noted that this protocol is comprehensive, although it may conflict to some degree with The Children and Family Services Act. We noted that the abuse protocol (dated February 1993) was not part of the CTC policy manuals (see section above on Communication and Consistency).

The Committee met with two families who had alleged that their children had been abused at the Dartmouth CTC and both families presented written declarations.

Parents who currently have children in the CTC indicated to the Committee that they felt their children were safe. Some suggested that a move away from the CTC is a move away from safety and security. Protection from physical and sexual abuse may, in their view, be less definite in a community setting.

Not all children have an active community advocate to ensure their identity as "important people". Visitors are clearly welcome at the Sydney CTC but possibly have been made to feel less so in Dartmouth. Both dialogue with Mr. Dawson and our literature review clearly indicated that openness of a facility is a major deterrent to abuse.

Although a good course in prevention of abuse is now available through staff training, only senior staff and a minority of line staff have been trained.

The Committee Recommends:

- 3.1 That the CTC policy manual explicitly indicate both zero tolerance for abuse of any kind and an obligation to report any suspicion immediately.
- 3.2 That staffing ratios must be such that individual staff members can be relieved for a period of time if they either feel or appear to be under great stress.
- 3.3 That the Department of Community Services consider the introduction of a personality screening device for new staff. While this may not apply to existing staff, it could be used in future to screen potential staff for CTCs and workers for new small option homes.
- 3.4 That present policies be continued so that at night there is always a mix of male and female staff and that personal care be carried out by same gender staff.
- 3.5 That regular visits from parents and/or advocates be encouraged through an "open door" policy.
- 3.6 That all staff receive training in the prevention of abuse. All staff should have completed this training by May 1, 1995.
- 3.7 That the Department of Community Services' "Physical Force Policy" be made congruent with the training provided to staff on Non-Violent Crisis Intervention. /

4. Education

All eligible residents in the CTCs attend public school with the exception of the Nursing Unit population at the Sydney facility. It was noted that all are in segregated special education classes and only one instance of partial integration into a regular class for one resident was reported.

In Dartmouth and in Sydney, the Committee visited two of the three sites where CTC residents attended school. In both cities, significant differences were noted between the two sample schools.

In Dartmouth, the physical setup of one class was inadequate, with neither washroom facilities nor running water available within the classroom. In that same situation, the space was very cramped for the number of students and the equipment. The teacher reported that there were too few personnel available to carry out many elements of a program that she would consider appropriate. Even such simple activities as a walk in the neighbourhood were impossible because of limited human resources. The Committee observed a marked contrast in the second Dartmouth location, where there were many adults engaged with the students and a great variety of activities being carried out. The level of involvement, familiarity with the program, and commitment to the students demonstrated by school administration appeared proportionately greater in the latter situation as well. The difference in the two settings can best be described as one of optimism and enthusiasm contrasted against one of discouragement. Discussions with a school board official indicated that there was some considerable concern about funding a costly program for a large number of students who were only residents of Dartmouth by virtue of their placement at the CTC. This concern has been addressed to the Premier by the School Board.

There was a similar contrast between the two locations in Sydney. In one instance, the students were observed in two teaching areas, both of which were well suited to the activities carried out there. A number of adults were present and there was a sense of "team" in the way that they interacted with their students. In the second situation, the physical setup was spacious and well equipped; however, there was a diminished feeling of productivity. The most notable single concern

was the use of the school day. When the Committee arrived at this location, shortly after the noon break, the CTC residents were being loaded into the bus for the drive home. After spending some considerable time at that location, the Committee moved along to a second school, observed students in two teaching areas, carried on a conversation with staff and, upon leaving the building, observed the bus with the students from the first school still aboard coming to pick up the children from the second class. Questioning revealed that this was a daily practice where these young people travel all over the city, spending up to two hours on the bus ride home. This is a distressing waste of time and should not be tolerated.

Having reviewed a number of Individual Education Plans, it was the Committee's observation that they were of variable quality, had limited integration with the individual program plans in the CTCs and were not reflective of planning or training for a transition to community placement. There was almost no involvement of parents and limited involvement of CTC staff in their development.

The teachers in both school systems had consistently high praise for the level of cooperation from CTC staff ; however, it was usually phrased in terms of "anything that we ask them to do will be done". There was no real indication that the relationship was an interactive, shared decision making process.

The CTC staff appear to be grateful to the school system for "allowing" residents to attend school. This results in a less than assertive, proactive role being carried out in seeking the best programming for these children and youth.

The Committee noted that the two classes where they felt less positive about programming had a higher proportion of CTC residents than those which they viewed more favorably. The lack of a strong lobby for improvement may be part of the problem.

The Committee Recommends

- 4.1 That the facilities used for educating CTC residents be properly staffed and equipped, as well as physically appropriate to the needs of the students and the demands of the program. The situation in Admiral Westphal School needs to be addressed as an urgent priority.
- 4.2 That the transportation system for CTC residents in Sydney be changed immediately, in order that travel time be minimized.
- 4.3 That all opportunities for inclusion with the regular school population be pursued, explored and taken advantage of, in both instructional and social contexts.
- 4.4 That staff at the CTCs become more proactive in assessing whether or not the programs and facilities are (a) appropriate to the needs of the child, (b) consistent with the goals of the plan in place at the CTC, and (c) oriented to the acquisition of skills which will assist the students as they move into community placements.
- 4.5. That there must be a closer relationship among parents, CTC staff and school personnel working together for the benefit of the residents. The exclusion of parents from decision making and the passively appreciative approach of the CTC staff may not be in the children's best interests.
- 4.6 That, as children move to community placements, parents, CTC staff, school board and Department of Education personnel do careful planning to ensure appropriate placement and programming in the least restrictive situation.
- 4.7 That older residents, no longer eligible for public school programs, be provided with vocational opportunities and/or Continuing Education programs in the community or at the CTCs.

5. Individual Program Planning

Currently, an IPP exists for every resident in both CTCs, except those in the Sydney Nursing Unit. These IPP's were developed within the last year. Although IPP's exist, it is difficult to know how much follow through there is on stated objectives. Given the limited staff complement and resources, especially consultative services, it is highly unlikely that all the goals stated on the IPP's are attainable.

Files at both facilities were carefully examined. The Program Coordinator in Dartmouth initiated the IPP process. Parents, a key counsellor, a representative from Administration, and the community school teacher are invited to participate. Comments from eight parent representatives indicated that the process was worthwhile. Before this process was initiated, parents were primarily concerned with the safety and security of their children.

In Sydney, the full time CTC based teacher arranges IPP meetings for each resident. An invitation to attend the IPP meeting is extended to parents, advocates, an administrative representative, line staff, a Resicare worker and the public school teacher. Parents were pleased to contribute to the development of their children's IPPs. Before this process was implemented, parents received a report from CTC staff on an annual basis, updating them on their children's progress. Parents viewed the IPP process as a positive step.

Five different sets of files exist on each resident of the Dartmouth facility. The file maintained by the Program Coordinator contains the IPP on each resident. The goals and objectives stated for each resident appeared to be realistic, however, recorded information suggests that progress by each resident has been minimal.

Although staff expressed an interest in delivering appropriate programs to individual residents, staffing problems and patterns often interfere.

In July of 1993, a Staff Training Officer from the Department of Community Services was seconded to develop programs in Dartmouth. A small group model was developed and the children were divided into six different groups. Staffing had been enhanced and the staff to resident ratio improved dramatically. For several months following the implementation of the small group model, both the staff and residents appeared to benefit from this change. The atmosphere at the CTC was reported to be less stressful and the children enjoyed extra attention and stimulation. The staff also felt better about their accomplishments. When the staff to resident ratio was at its highest, individual programs were being carried out more consistently. Programs would have been further enhanced had designated staff worked consistently with specific groups; however, this was determined to be impractical by CTC Administration. Unfortunately, since the commencement of this Review, staffing has been reduced on four occasions and, predictably, services to the residents have deteriorated, as has staff morale.

The Sydney CTC has never experienced an influx of staff similar to Dartmouth. They have always operated on a low staff to resident ratio. The staff teacher in Sydney is largely responsible for ensuring that goals are set and worked towards for each resident. The Sydney CTC has changed its focus somewhat in the past year and, instead of working on more traditional, cognitive tasks, their focus is now primarily on life skills training. Stated goals found on their IPP's include using a spoon and/or fork, walking in the neighbourhood, climbing stairs, walking on uneven terrain, using a face cloth, etc. The staff in Sydney are quite innovative and resourceful in that they not only work on independent living skills in the CTC,

but they practice them in the community. The teacher is largely responsible for scheduling community outings for this purpose.

It has essentially been left for staff in both facilities to attempt quality programming on their own. Both CTCs appear to have very limited access to external consultants. In Dartmouth a psychologist has seen one child because of his behavioral difficulties; however, the funding for this specialist was provided by the Children's Aid Society. Sydney has had occasional consultation from a Psychology Technician who is employed in another residential facility.

Staff in both facilities expressed a need for increased access to consultants. Behaviour modification and speech-language intervention were frequently described and observed to be lacking during the Review. Day programming for residents over the age of 21 was also a voiced concern. In Dartmouth, only one resident went out to a day program (DASC) and, in Sydney, they are still waiting for a 24 year old female to be accepted by the Kin Center. Many residents in both CTCs are no longer eligible to attend school due to their age, yet they have not been able to access community vocational day programs.

The Committee, as well as some parents, felt that such equipment as the whirlpool, the trampoline, and the playground appeared under-utilized. It is also relevant to note that, in the Dartmouth CTC, residents were observed to retire for the evening much earlier than would their peers in the community.

The Committee Recommends:

- 5.1 That the consultative services of a behavioral psychologist be utilized on a continuing basis to address the needs of residents. This individual should also assist staff in the development and implementation of programs for residents.
- 5.2 That a speech-language pathologist be readily available to assist in developing alternate ways for residents to communicate.
- 5.3 That the IPP program must be monitored and revised on a regular basis. Program reviews which involve parents and CTC staff should be carried out at least every four months.
- 5.4 That a goal of each IPP be the development of life skills necessary for the transition to community living. Individual programs must always include objective assessment procedures.
- 5.5 That an age appropriate bedtime be established for each resident.
- 5.6 That staff teams be designated to work with specific residents in order to enhance the level of consistency in their programs.

6. Involvement in Community Activities

To assess the residents' involvement in community activities, the Committee reviewed file documentation at both CTCs, solicited input from parents and other family members; and held interviews with line staff and administrators.

According to the information gleaned from individual files in Sydney, the staff there attempt to make daily trips into the community with some residents. Five or six children can be transported in the CTC van at any time and two to three staff accompany these children on their outings. Taking the children out in the van in Sydney is no easy task, as many children are wheelchair bound and the Sydney CTC van is not equipped to accommodate the chairs. It does not have a hydraulic

lift and, consequently, staff members have to lift both the wheelchair and the child in and out of the van. Despite the inconvenience and the physical demands on staff, they still appear committed to ensuring that the residents have regular outings from the CTC. The Committee encountered a vehicle much more appropriate to such activities when they visited the Evergreen Home for Special Care.

Community outings vary from going for a drive, to stopping at a beach to play in the sand and swim during the summer months. Picnics are often incorporated into the daily summer schedule. Year round efforts are being made to take children to restaurants, swimming pools, bowling alleys, and local malls. This reflects an attempt to prepare them for life in the community following the closure of the CTC. It is also evident that children from the CTC in Sydney attend community events such as the Shriners Circus, winter carnival, and parties at the local Legion.

With the exception of the children in the Nursing Unit children in Sydney, all residents participate in community outings. Because of their medical conditions, these youngsters are not included in trips into the community. However, they are frequently taken out on the grounds of the CTC for fresh air and sunshine. The rationale behind excluding these children from community outings is that staff, in general, do not feel they have the expertise to intervene appropriately should an emergency medical situation present itself.

Every summer, children from the Sydney CTC attend Camp Canso. This past summer five residents went to camp, accompanied by one CTC staff member. One resident participated in a day camp program offered in the Sydney area.

An annual summer Fun Fest is held at the Sydney CTC, which is well attended by family members. Unfortunately, the Social Workers responsible for the welfare of the five CTC residents who are wards do not attend this event. A letter was forwarded to the appropriate social worker by the CTC staff noting their absence and providing the Social Worker with a description of how their child enjoyed the celebration.

Dartmouth CTC residents also participate in community outings, but the frequency of their outings is contingent upon staff availability. Both the gym and swimming pool at the Nova Scotia Hospital have been used on a fairly consistent basis. Out of center activities include going to community events such as the Ice-Capades, the Circus, concerts, basketball games, etc.

According to staff members at the Dartmouth CTC, liaison with the metro community has been excellent. Numerous organizations appear to be supportive of the CTC and host various parties for the children. Organizations such as the Halifax Kennel Club, Halifax Line Dancers, Esso Retirement Club, Waverley Bikers Association, Halifax Irish Dancers, North Preston Rappers, Dartmouth City Regional Library, I.O.D.E., and the N. S. Hospital are but a few who deserve special acknowledgment for donating their time and resources to Center residents.

All but two Dartmouth CTC residents participated in a summer camping experience. Ten children attended Camp Hilles, operated by the Department of Community Services in Annapolis County, four children went to Camp Canso and three children participated in an overnight camping trip with staff from the Dartmouth CTC. A young man with severe behavioral problems did not attend camp and one girl was unable to attend camp because she was hospitalized.

Six children from the Dartmouth CTC had an opportunity to involve themselves in summer day programs. Three residents participated in the Summer Intervenor Program sponsored by the Deaf-Blind Association; two children went out on a daily basis to the City of Dartmouth recreation program and one child attended a daily summer program offered by the Sackville Recreation Department. She was transported the 100 kilometres each day by her mother.

For those individuals who were not involved in summer day programs offered outside the CTC, opportunities were provided to do something in the community. Two vehicles, the CTC van plus a second van on summer loan from the Nova Scotia Youth Training Center, were utilized by Dartmouth CTC staff on a daily basis. Outings in the vans were generally planned with specific destinations in mind such as beaches and parks, (e. g. Point Pleasant Park, Shubie Park, The Wildlife Park, etc.). A picnic lunch was often packed for these outings.

Following the staff increases in 1993, community outings increased. With the current decrease in staff, trips into the community are more difficult and less frequent. The impact of the staff decrease is particularly noticeable between 2:00 p. m. and 8:00 p. m. daily.

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During several visits to the Dartmouth CTC, it was observed that an activity calendar which was posted on the wall gave little information about upcoming planned events for CTC residents. The residents' success in leaving the CTC building appeared very much dependent on staff resources and whether the staff was aware of what was happening in the community. Although it is commendable that some effort was being made to schedule community outings, it was apparent that this process lacked planning and coordination.

The Committee Recommends:

- 6.1 That a staff person be assigned to plan the monthly schedule of events for CTC residents. This responsibility could be assigned on a rotating basis, so that all interested staff have an opportunity to provide leadership in this area.
- 6.2 That the children in the Sydney Nursing Unit be given an opportunity to participate in community outings. Staff with appropriate medical training would accompany these children.
- 6.3 That a larger, lift equipped bus be made available to each CTC.
- 6.4. That stronger links be established between CTC Administration, Parents and Municipal Recreation Departments in order to expand the participation of CTC residents in community activities.
- 6.5 That the CTC staff carry out a minimum of two outings with each resident every week. The outings should focus on the transition to community living (e. g. use of transit, shopping for personal needs, eating out in restaurants).
- 6.6 That the CTC staff assist residents in establishing age appropriate social interactions (e.g. Junior High dances, Girl Guides, Scouts).
- 6.7 That the residents be afforded regular opportunities to be supported in activities which they prefer or ones that their families feel they would enjoy. Residents should be exposed to a variety of activities in order to determine their likes or dislikes.

7. Social Networks and Supports

A strong social network is important for successful community adjustment for persons both with and without handicaps. Despite dramatic shifts in attitudes and services provided to individuals with handicaps over the past twenty years, many of those people de-institutionalized still experience a high degree of social isolation. While it may be disappointing, it is not then surprising to discover that the children and young adults living in both CTCs have very limited social networks,

especially outside the facilities. The residents' primary social contacts are with paid staff members and family. Fortunately, these are mostly strong and positive associations.

Most of the children do not have any special friends that visit them on an ongoing basis. Exceptions were found at both CTCs. Two children in Sydney maintain individual relationships with two former staff members from the CTC. In Dartmouth, one child has visits with a former community recreation worker.

Few of the children and young adults have memberships in clubs or organizations or attend recreational classes in the community. However, in Dartmouth, one of the boys attends a local cub group regularly. This was initiated by his key counsellor and a male counsellor from the CTC accompanies him. Another child from the Dartmouth CTC attends church on a semi-regular basis supported by staff from the CTC..

The CTC residents appear to have little contact with their neighbours. In Sydney, one of the neighbours is a former Administrator of the CTC and he still visits the children. Another neighbour, who is physically challenged, will occasionally socialize with the residents if they are outside. In Dartmouth, the CTC has a cooperative relationship with the Nova Scotia Hospital, situated on the adjacent property. The children walk on the grounds and use some of the facilities.

There are no volunteers at either CTC. Dartmouth staff noted that they had tried this in the past and that those who came seemed to have difficulty relating to the children and/or lost interest. In Sydney, staff also reported little success in finding committed volunteers.

Some children within the CTCs do show preferences in peer interactions. Staff appeared to be aware and supportive of these relationships. In Sydney, staff supported the friendship of two adolescent girls by helping them set up a room they could share and decorate to their own tastes. CTC staff and parents acknowledge the relationship, saying they are "like sisters". Special efforts, like that of the Sydney staff should be encouraged and expanded upon in both CTCs.

While some of the IPP's focus on managing inappropriate social behaviour, there does not seem to be a great deal of emphasis placed on speech and communication programs. The consulting psychologist in Dartmouth commented that many aggressive and inappropriate behaviours of the Dartmouth CTC residents likely arise out of frustration with their inability to effectively communicate their needs and preferences. Only a few children in both facilities have individualized communication programs. The CTCs do not have regular access to speech and language pathologists and service through the school system was reported to be quite inaccessible.

Mealtimes are important potential opportunities for socialization. The Review Committee observed mealtimes at both CTCs on a number of occasions. Both have separate dining rooms for staff and residents. This is not the case in other facilities operated by the Department of Community Services such as the Nova Scotia Youth Training Center or the Nova Scotia Residential Center where children, staff members and visitors eat together cafeteria style. The practice, observed at both CTCs, of seating children at individual tables appears designed to accommodate the needs of the staff to simply get the residents fed or to supervise efficiently, rather than to facilitate a pleasant, social mealtime. Continuing this practice potentially creates or perpetuates another barrier for the children to overcome when placed in the community.

In recent years, the trend has been to address the social inclusion of individuals with developmental disabilities through person-centered planning processes. Various approaches have been used to develop and implement inclusive education programs for children and youth with disabilities. Locally some families have tried "circles" of support to expand their children's network of friends with varying results. As the Committee spoke with parents and Community Service providers, it became apparent that, although this is a very challenging area, it is also an important need. Fostering personal networks for the children has not been tried at either CTC.

The Committee Recommends:

- 7.1 That a Community Advisory Committee be formed for each CTC. It would provide for Community representation, including neighbours and parents. Terms of Reference for the Committee might include developing strategies to promote social inclusion and recruitment of volunteers with the goal of supporting transition to community living.
- 7.2 That a higher priority be placed on individualized communication programs for the residents, including regular consultation with a speech-language pathologist.
- 7.3 That the staff and children share one cafeteria. Children need to be seated at tables in small groups, rather than individually, in order to promote socialization and a more typical mealtime routine.

8. Parental Involvement

Parental involvement is often dictated by the personal circumstances of the family. Parental involvement with the CTC residents, their programs and progress has taken the form of telephone contact, in-center visits, out of center visits, signing the voluntary care agreement and invitations to attend Individual Program Planning meetings. In total, seven children between the two CTCs are the responsibility of

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either a Children's Aid Society or the Department of Community Services. Most Caseworkers assigned to these children have had minimal or no involvement in their lives.

Children with parents and/or family members (e. g. grandparents) experience varying degrees of involvement. Some parents or family members call on a regular basis, and others attempt to visit the Center or take their children home fairly frequently.

Overnight visits generally occur on special occasions (e. g. Christmas), with the exception of a few children who go home for week-end visits.

Some Parents from the Dartmouth CTC who are unable to take their children home for various reasons, expressed a degree of discomfort about visiting their children at that facility. A private and quiet visiting area was described as being a need for them.

Both CTCs have invited parents to attend parties held for the children at their facilities. Parents who attended with their children were reported to enjoy these social gatherings.

The pending closures have prompted parental involvement. Parents in Sydney, having rallied together on more than one occasion, managed to extend the life of the Sydney CTC. The announced date of closure has since been retracted. Parents with children in the Dartmouth CTC do not belong to a formalized parent group. Some parents associated with that facility once belonged to the CTC Family Support Group, now known as the Family Support Network of Nova Scotia.

Parents with children currently living in the Dartmouth CTC have minimal contact with one another.

The Committee Recommends:

- 8.1 That the CTC staff actively promote and support closer relationships between families and residents in the following ways:
 - a. Development of a pleasant, private family room where children can visit with relatives;
 - b. CTC staff actively encourage home visits by accompanying the children to their homes, if families are receptive;
 - c. Residents, with the assistance of staff, give parents/family members homemade cards or gifts on special occasions.
- 8.2 That, where possible, parents be encouraged to contribute to their child's quality of life by becoming more involved in their child's out of center activities, (e. g. taking their children to community teen groups).
- 8.3 That a parent group be established in both CTCs and support be provided for parents to attend.

9. Advocacy

The Review Committee discussed a number of issues with respect to advocacy. Parental roles, roles of social workers responsible for residents who are wards, the role of CTC staff in advocacy and the issue of independent advocacy were all examined.

There are some efforts in both facilities to involve parents in the decisions being made on behalf of their children. The process in the Sydney CTC was more concerted, less formal and more trusted by the parents. There appeared to be a better developed system of communication (through personal visits and telephone contacts) in Sydney than in Dartmouth. The administration of the Dartmouth facility, especially in years past, was reported to adopt a highly formal approach

as to whom a parent might make contact with or what issues were to be discussed. These practices diminish the level of trust that parents have in the facility. Concerns were expressed with respect to a lack of communication, especially in reference to injuries, illness and required medical treatments. These had not always been reported promptly to parents by staff of the Dartmouth CTC.

Describing counsellors as "advocates" for the residents needs clarification. The term advocate implies that the person will always act in the best interest of the resident and has no conflicting loyalties. In reality, if serving the residents' best interests contravenes the existing policies or procedures of one's employer, a true advocacy role is inevitably compromised. The Committee saw no difficulty with Counsellors having extra responsibilities for specific residents; however, "key counsellors" or other designation would be more appropriate than "advocate".

The Committee was very concerned about the role which social workers play with respect to residents who are in the permanent care and custody of the Minister. It was distressing to note, through a thorough review of the files obtained from the Coordinator of Children in Care and from telephone interviews with three agency workers, that the contact and reporting mandated in Manual of Procedure: Children in Care and Custody of the Minister is simply not being carried out. Annual reviews on several CTC residents were observed to have been completed by CTC staff and only co-signed by the agency worker. One resident's annual reports were filed in only five of twelve years in care.

One resident has only two annual entries in her file (the last being in 1987) and was described by the agency casework Supervisor as "one of our forgotten children". The worker for another child who has been in care since 1978 and who is now a resident of the Sydney CTC indicated that he (the worker) has never

visited the facility. The same worker also indicated that any telephone contact was initiated by staff at the CTC and not by himself.

Obviously, this is not in keeping with the requirements of the Regulations to the Children and Family Services Act for a quarterly visit, regular contact and the development of life plans.

In sharp contrast, some files are up to date and both personal and telephone contacts are noted. One worker told the interviewer that in addition to regular visits to the CTC, a school conference had been attended by the agency staff.

Caseloads, distance, and confidence in the level of care at the CTCs were cited as reasons for the lack of contact. These are not acceptable reasons in the opinion of the Review Committee. Workers should be compelled to familiarize themselves with their responsibilities and be held accountable for carrying them out.

If lack of either knowledge about or comfortability with mentally handicapped persons is the reason for this serious failure of some agency workers to dispatch their responsibilities, an alternative might be to have all mentally handicapped wards become the responsibility of one or two workers who are both interested and appropriately trained.

Several parents indicated their appreciation for the role of an independent advocate during their dealings with the administration of the CTCs and/or the Department of Community Services. When CTC administrators communicate with parents and, more especially, when the transition negotiations for community

placements are in progress, the opportunity for parents to involve independent advocates as supportive participants in the process must be clearly communicated.

The Committee Recommends:

- 9.1 That the administration of the CTCs and their staff involve parents in all decisions which affect their child's well being. This would include IPP conferences, discussions of school opportunities, medical consultations, etc.
- 9.2 That social workers who are responsible for the supervision of those residents who are wards be made accountable for carrying out their mandate as outlined in the Manual of Procedure and in the Regulations to the Children and Family Services Act concerning visitation and reporting.
- 9.3 That the term "advocate" not be used in relation to counsellors' duties and be replaced by a more appropriate and less misleading designation.
- 9.4 That advocates be recruited from the community for children with infrequent visitors and for those with no legal guardians.
- 9.5 That the role of the independent advocate in supporting parents be affirmed and communicated.
- 9.6 That "crown advocacy" and a system of Advisory Committees on residential placement, as are mandated in the Province of Ontario be examined and possibly adapted to a Nova Scotian context.
- 9.7 That relevant training be provided to those social workers who are responsible for mentally handicapped children in care.

10. Respite

The CTCs have provided an out of home respite option for families for many years. Some families use the CTCs on a regular basis for planned breaks (e.g. regularly scheduled weekends or for vacations), while other families use respite services at times of crisis. The CTCs currently have a no permanent admission policy; however, some children have been admitted for "long term respite".

In Sydney, nine children have used the respite service in the past year, one on long term and another on a very regular basis. In Dartmouth, there are three children at the CTC for long term respite. In recent years, about ten other families in total have been using the CTC for occasional respite. Respite admissions have decreased over the past year and there are currently about four families who regularly use the CTC for short term respite.

Staff in both CTCs view their roles in providing respite as positive and supportive. The only concerns noted were that some children who might need respite are less handicapped than the regular CTC residents or have very challenging behaviour and, therefore, require a different type of programming. The CTCs seem able to accommodate relatively low numbers of children for respite without too many difficulties for residents or staff.

Many parents spoke passionately to the Review Committee about the need for both in-home and out of home respite. A concern repeatedly articulated, was that respite needs to be on an "as needed" basis. Limits of twenty eight days or arbitrary formulas do not work well for families. Parents also said that the In-Home Support program needs enhancement and better advertisement in the community. Many parents felt they found out about the CTC and in-home support services by accident or by word of mouth.

In the follow-up survey of Parents and Guardians of Children who have moved from the CTCs since 1991 (Appendix B), families who formerly used the Pictou CTC for respite were contacted. One family is using the Dartmouth CTC for respite, two now use an Adult Residential Centre, two use in-home respite providers and two now rely on family members. While most families seem satisfied with their new arrangements, there was inconsistency in the amount of support

they received in finding new arrangements. Parents' needs for respite vary and it would seem essential that there be a flexible continuum of respite options available so that families can choose the arrangement that best suits their needs at a given time. Clearly, some families require or prefer out of home respite at some times. When CTCs close, options for out of home respite will need to be provided in some other way. Programs which are working well in other provinces might provide some models.

According to the Minister's Advisory Committee on Services to Children with a Mental Handicap, the need for respite was identified as the highest priority by parents and professionals. The recommendations from the Report regarding respite have yet to be fully addressed. The Review Committee supports the two recommendations made on Respite. The Department's Project Team, scheduled to be put in place in the fall of 1994 would ideally follow-up these recommendations so that there is no disruption in services to families when CTCs close.

The Committee Recommends:

- 10.1 From the Minister's Advisory Committee on Services to Children with a Mental Handicap:
 - a. That a respite service be developed. Where it is determined by the family and the case manager that respite services are required, these must be tailored to individual families' needs;
 - b. That funding be made available to non-profit community based boards to establish respite services for short term care. These services must be available province wide.
- 10.2 That the Department's Project Team oversee the development of an improved respite service system with both in-home and out of home options.
- 10.3 That the Department widely and clearly communicate its policies and services in relation to respite to families of handicapped persons, professionals and the general public.

11. Administrative Support

The administrative staff in the two CTCs operate in a noticeably different manner. The retiring Superintendent of the Sydney facility and the Acting Superintendent who has succeeded her were consistently described by staff and parents as being approachable, open and extremely "hands on" in their approach. The Review Committee noted that, without fail, in hours of discussion with both persons, that they were totally knowledgeable and extremely forthright in their responses to our questions. That openness appears to engender the high level of parental trust that is so obvious.

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The situation in Dartmouth is less easily assessed. The previous Superintendent was seen by some as secretive and authoritarian in her dealings with parents, especially if they questioned or expressed dissatisfaction with the CTC's handling of or programming for their child. The Committee was able to examine some correspondence (the very fact that written correspondence rather than personal contact was used on some issues was, of itself, unusual) which confirmed that communication was not always cordial and collegial in nature. The incumbent Acting Superintendent and the Acting Assistant Superintendent certainly get better reviews from most parents; however, there is an aloofness which appears to separate the "front office" from the rest of the CTC that was not paralleled in Sydney.

The Committee was concerned that the Assistant Superintendent in the Sydney CTC reported spending up to eighty percent of her work day doing staff work schedules. This aspect of the operation should be addressed at both CTCs.

It is unclear why both the Superintendents and the Assistant Superintendents in both facilities are Registered Nurses. The need for enhanced program planning for residents and the general administration of the facilities could benefit from other areas of expertise.

The role of Senior Counsellor should be reexamined. It would appear that these persons are often so caught up in work which parallels that of line staff that their potential for leadership and staff direction is unfulfilled.

Staff in both facilities reported extreme difficulty in holding comprehensive staff meetings. The lack of such opportunities impacts negatively on program planning.

The Committee was not certain that the administrative staff pursue staff training or expert consultation for their staff as vigorously as they might. Both are areas that the Committee sees as being wanting.

Mechanisms for staff evaluation and for evaluation for administrators appear to be in place and to be used. All the Administrators interviewed appeared to feel supported by the Department of Community Services Head Office staff and by their own staff.

In Dartmouth, a senior counsellor and line staff reported spending excessive time in redundant reporting. The same information is recorded in several different files and the recording may take up to an hour of each staff member's working day.

The Committee Recommends:

- 11.1 That communication procedures and styles between the Dartmouth CTC and parents be reviewed and amended as required in order to ensure that it is responsive and open.

- 11.2 That the role and job description of Senior Counsellor be reviewed to ensure that they are expected and have the opportunity to provide leadership to line staff.
- 11.3 That the practice of having both Senior Administrators trained in nursing be reviewed. Several other fields of training have the potential to benefit CTC residents.
- 11.4 That computerized staff scheduling software be purchased immediately in order to allow the Assistant Superintendents to use their expertise for the direct benefit of residents.
- 11.5 That recording practices be reviewed and redundancy eliminated.
- 11.6 That regular comprehensive staff meetings be held to discuss the programming needs of residents.

12. Staffing Levels

The CTCs were initially opened in 1969 to provide custodial care and training to children with mental handicaps who could no longer live at home or in foster care placements. The predominant model of care at that time was an institution-based medical model.

Over time, as philosophies and models of care shifted to be more community focused, the CTCs have been attempting to teach more severely handicapped children basic life skills such as feeding, dressing and toilet training so that they can eventually return to their homes or non-institutional settings. At the same time, the resident population at the CTCs has changed. While there are now fewer residents, the present population appears to have more severe handicaps, and include children with multiple handicaps, and/or significantly challenging behaviours.

Despite the changes, the staff complement at the CTCs had not changed a great deal over the years. Many permanent staff at the CTCs have worked there all of their adult lives. The average employee in Dartmouth has 13 years of tenure and in Sydney 20 years. There is little turn over in permanent staff positions at the CTCs.

Recent government wide restrictions in hiring and policies of fiscal restraint have had a negative impact on staffing in the CTCs. As permanent staff left or transferred, positions were filled on an acting basis or by casual staff. In both CTCs, the two senior administrative positions are currently being filled by "Acting" or "casual" staff.

In the Head Office of the Department of Community Services, several divisional positions including the Director of Services to the Mentally Handicapped are being filled on an "Acting" basis.

The multiple effect of this practice creates an atmosphere of impermanence and potential instability. Acting or casual employees may not feel able to institute needed changes, may not have perceived status with staff and the Department may not invest in casual staff to the same degree as permanent employees. The rate of pay and the level of benefits for casual staff are lower than for permanent staff. This can become problematic over time, especially for staff morale.

The Committee were told of the effects that budget restraint is having on the operation of the CTCs. Not filling maternity leaves, sick leaves, vacant permanent positions and the required unpaid leave days in the past year have meant fewer counsellors to care for children. Superintendents have routinely requested permission to fill these vacancies, but have not generally been able to do so.

Where they have been able to hire, there have been months of delays. While the accumulated effect saves the government funds, this seriously diminishes the quality of care to the residents.

Within this context, a crisis emerged in the spring of 1993 at the Dartmouth CTC. The Acting Superintendent stated that it was not unusual then to have 120 incident reports of injury to children and/or staff per month. When staffing levels were dramatically increased, the rate of incidents decreased dramatically and immediately. Increased staffing improved the quality of individualized programming and community outings increased. The children were busier and seemed happier. Staff morale improved, as counsellors felt better about what they could accomplish with the children. Parents also noticed an improvement in the quality of life for their children and felt greater confidence in the CTC program.

During the Review, over approximately six months, the Committee found that staffing levels in Dartmouth had been reduced four times to meet internal budget guidelines or government policy on fiscal restraint. While the staffing schedule has not been reduced to the low level of the spring of 1993, it has had a significant, negative impact on the promising changes that were taking place.

Front-line staff at the Dartmouth CTC report that they currently have less time to spend with the children and administrators acknowledged some IPP's cannot be implemented now. There are more children in each program group resulting in a lesser quality of programming. There has been an increase in attention-seeking behaviour from the children in Dartmouth. Some staff at the Dartmouth CTC feel disillusioned because promises of maintaining the enhanced staffing levels and securing consulting resources have not been kept.

The Review Committee members visited a Small Option Home and noted that staff to child ratios in Small Option Homes appear much higher than in the CTCs. The high level of staffing in the Small Options enables the children to have a great deal of personal attention and supervision, as well as frequent community outings. While some parents of children currently in CTCs express concern over the level of staffing in the community residences, this fear does not appear to be well founded. As the follow-up survey demonstrates, the children who were residents of CTCs seem to be flourishing and parents are well satisfied with the staffing and programs in Small Options.

An adequate level of staffing appears to be one key to ensuring a high quality of life for the children as long as they remain in the CTCs. Without these enhancements, the Committee feels it is impossible to ensure the safety, security and development of the residents.

The Committee Recommends:

12.1 That staffing levels be increased in both facilities to the enhanced level achieved in September of 1993 at the Dartmouth CTC. If this is deemed impossible due to fiscal restraint, then the Department of Community Services should accelerate the planning for closure and cease operations at both facilities at the earliest possible date.

13. Staff Training

One measure of quality in residential programs is the expertise of the people providing the services. The Committee examined pre-service qualifications of staff, as well as orientation and in-service training of staff. Profiles of counsellors, individual training transcripts, Facility Orientation Manuals and staff training plans

were reviewed. Superintendents of the CTCs and Staff Trainers for the Department of Community Services were interviewed.

An analysis of Counsellors' pre-service qualifications revealed that more than half of the permanent staff held a certificate in early childhood education or the Nova Scotia Institute of Technology program in Community Services or Adult and Child Care. Senior Counsellors in Dartmouth had more than 18 years work experience in the facilities; but no formal educational qualifications. Casual staff often have University undergraduate degrees, in sociology, psychology, history, etc. but do not necessarily have practical training in behaviour management, child development or program planning. A few staff in each CTC have degrees that are relevant, like Special Education or Early Childhood Education - with a specialization in Developmental Disabilities. Administrators at the CTCs are nurses who have had experience working in residential facilities for children or adults. All have taken courses in supervision or management.

Currently, neither CTC is affiliated with any of the pre-service training programs or universities in the province that have student practica.

Both CTCs conduct orientation for casual and permanent staff and have Orientation Manuals for their facilities. Once orientation is completed, forms are signed by both staff and Administrator and copies are placed in personnel files. The systems in place seem adequate, effective and well established. The Committee felt that content could be added or updated in such areas as values and service principles focused toward future community living, working with parents and families as partners, and epilepsy. Overall, orientation is an area that both CTCs appear to be accomplishing well.

Training needs in both facilities are assessed on an annual basis. Dartmouth CTC has its own Staff Training Committee, which discusses training needs and plans in-house training. Training plans are developed for the year and submitted to the Training Unit and a Head Office Division representative. Content areas addressed by recent in-service training plans were Individual Program Planning, First Aid, Facilitated Communication, Gentle Teaching, Non-Violent Crisis Intervention, Recording and Professionalism to name a few. Not all permanent staff have received all training provided due to shift schedules. Casual staff did not regularly receive training prior to 1993.

One of the few required or mandated training programs at the Centres is the two day workshop on ***Non-Violent Crisis Intervention***. The emphasis of this program is to prevent crisis situations and to de-escalate individuals effectively before acting-out behaviour occurs. All staff in Dartmouth have been trained but it is unclear how well the training has been transferred to the job. Some line staff have reported that the training was useful but that they do not see all staff implementing the new concepts or practices at the CTC. In Sydney, only some staff have taken the training. Since both facilities now have staff members who are trained as trainers in this area, this should provide universal access to this program.

In the fall of 1993, the Department contracted with the ***Institute for the Prevention of Child Abuse*** to provide comprehensive training for Senior staff and subsequently for line staff in all Department facilities on ***Preventing Abuse in Children's Residential Facilities***. Eleven CTC staff have completed this training to date. The Committee met with the facilitator of the workshops, Ross Dawson, and reviewed the training manual. The Committee was very satisfied with this training program and the manual provided to staff, but feels CTC staff are not receiving high enough priority for spaces in the programs.

In the past year, the Training Unit has facilitated several joint meetings with Superintendents of all the facilities operated by the Department to share information and to ensure CORE Training is available to staff in institutions. The current trend is to have all staff trained in several key areas such as Non-Violent Crisis Intervention, First Aid and CPR, Preventing Abuse in Children's Residential Facilities and Preventing Sexual Harassment (a government mandated program for all employees). These priorities are reflected in the training plans developed for the coming year.

Problems were reported in freeing up staff to attend training programs due to shift work, schedules and funding needed to replace staff. This can limit the number of training programs staff can attend. The Superintendent in Dartmouth indicated that the recent reductions in the budget line for casual staff may preclude staff receiving even the minimum, mandatory training. As well, staff are no longer paid to attend training programs due to budget restrictions. Despite these difficulties, staff are motivated to learn. This is evidenced in the fact that Dartmouth CTC staff watch video training programs and read related materials on quiet night shifts.

Training outcomes are not clearly defined for most programs and changes in staff performance are not well documented, although the Superintendents report seeing some. There may be some barriers to staff transferring learning from training programs into the workplace. For example, staff may not receive enough positive comments from senior counsellors or Administrators for trying new skills or there may be a delay in all staff receiving the training which can cause inconsistency.

Quality assurance mechanisms need to be strengthened around training in the CTCs. While there are a number of people involved in the development of the annual Training Plan, Superintendents are not held accountable if training does not

take place. No summary reports are required at the end of the year and it seems unclear as to whether this is addressed during the Superintendent's annual performance appraisal. One Superintendent said it was and one said it was not.

To date, the Department has not placed a great deal of emphasis on the transition that staff will be required to make, as plans are made for community living. The staff of the Dartmouth CTC have known closure was a possibility for a few years and some staff have been preparing for re-employment by taking University and other courses. Most staff at the Sydney CTC have not begun to retrain or consider future options.

The Committee recognized that the CTC Administrators and staff could assist the children and families with the transition to community living. The positive support of these caregivers will be important; yet, many have neither a philosophical base nor extensive knowledge about community services. An intensive staff orientation program to the community will need to be developed and begun immediately.

The Committee Recommends:

- 13.1 That CTCs support relevant pre-service training and education programs that include practicum experience.
- 13.2 That Orientation Manuals be revised and updated to include:
 - a. values and service principles that are consistent with current philosophy in the field, with a focus toward community living;
 - b. working with families - an understanding of parents' roles and needs and methods of including parents as partners in the care of their children; and
 - c. epilepsy - a more in depth and updated discussion on seizures and how to care for children with epilepsy.

- 13.3 That all Counsellors including Casuals and Senior Counsellors have training in Core areas of competency. Core competencies should include First Aid/CPR, Non-Violent Crisis Intervention, Individual Program Planning and Behaviour Management.
- 13.4 That the new staff training program, "Preventing Abuse in Children's Residential Facilities", in cooperation with the Institute for the Prevention of Child Abuse be continued and all line counsellors complete this training in the next six months.
- 13.5 That quality assurance mechanisms be adopted by the Head Office Division and Staff Training to ensure training occurs as planned and that effective strategies are employed so that training is fully utilized on the job.
- 13.6 That Teachers and Program Coordinators in both facilities undertake additional training and coaching in Individual Program Planning and Behaviour Management so that they might provide a stronger leadership role in those areas at the CTC.
- 13.7 That the Department of Community Services undertake the development of an intensive training program that will provide CTC staff with an orientation to community living, including value based workshops and visits to community residences. This program should begin by January 1995.

14. Funding

The budgets of the CTCs do not appear to have been based on current program goals. The original staff ratios were inadequate to achieve the goals stated in the mission of the CTCs. The characteristics of the residents may have changed over the years - currently there appears to be a higher proportion of young people with mental handicap and aggressive behaviour. Such residents are very demanding on staff time and require a high staff/resident ratio. Budget determinations based solely on staff/resident ratios fail to recognize the individual challenges presented by many of these young people. The current reduction in staffing at the Dartmouth CTC can only be viewed as arbitrary, as was the dramatic increase of last year.

The 1993 staff increase for the Dartmouth CTC, with no comparable increase in Sydney, is not easily justified.

The total cost of care for these children in a community setting could approximate that of the CTC placement, but only if staff wages are less in community placements. High quality community placements for CTC residents are likely to increase demands for similar services for young people currently living at home.

The Committee recommends:

- 14.1 That the budget of the CTCs not be reduced by any arbitrary formula. The Committee did not recognize any more "efficient" ways of caring for these children. Virtually all suggestions for improvement call for greater staff numbers.
- 14.2 That a special interim budget be provided for the transition to community placement.
- 14.3 That a clear policy be developed by the Department of Community Services regarding supports for families whose children, now living at home, would have met the criteria for admission to the CTCs, prior to the admissions "freeze".

15. Transition Planning and Community Placement

The impending closure of the CTCs is viewed with a great deal of anxiety by many parents. Before 1992, nearly all new residential placements for persons leaving the CTCs had been to Adult Residential Centres. In 1992-93, children from the Digby and Pictou CTCs were placed in a variety of community or institutional settings. The Committee directed a review of the process of community placement from the Dartmouth, Digby and Pictou CTCs (see Appendix "B"). This review revealed a great deal of parental satisfaction with the outcomes of that process

and the current placements of their children. There were some criticisms from a small number of parents.

Senior officials from the Department of Community Services described the creation of a "Project Team" to facilitate transition from the CTCs to community placements. It was stated that this team will be functional in the fall of 1994.

The Committee Recommends:

- 15.1 That planning for community placement begin immediately. Each child's options should be considered by a team consisting of (at least) the parents, the Superintendent, a senior counsellor who has worked closely with the child, a representative of the Department of Community Services and, if the parent desires, an advocate of their choice.
- 15.2 That the final decision about the location and nature of the community placement must be approved by parents.
- 15.3 That parents of children currently within the CTC, have the opportunity for education about the possible options for community placement. This might be a series of information meetings and/or on site visits for parents. Parents with logistical, financial or other barriers should be supported in attending such meetings.
- 15.4 That a long term commitment for support of the CTC residents be made explicit. The Committee favours some form of individual financial commitment which can follow the resident if the community placement needs change in the future and as the individual moves from child to adulthood.
- 15.5 That parents continue to be linked together after closure of the CTCs so that satisfaction with existing arrangements can be assessed. As well, parents would be able to share experiences and provide mutual support.
- 15.6 That opportunities for CTC residents not vary because services and programs have not been brought to the attention of parents and caregivers or because some individuals are more aggressive in articulating their demands. Opportunity should be based upon the principle of equity in the availability of supports and services.

15.7 That once the outline for community placement has been made for an individual, their IPP/IEP in the CTC and at school (where applicable) be altered to help prepare them for the transition.

Client Profile

The Terms of Reference for the review directed the Committee to develop a "client profile" for residents of the CTC. At the time of the review, there were 38 young people living at the CTCs. They ranged in age from 6 to 24 years of age. Each child has particular areas of strengths and weakness that are not easily summarized.

At the request of the Committee, CTC staff directly involved in individual children's care, completed the California Adaptive Behaviour Scale to develop an adaptive age equivalence for each resident. This scale quantifies areas of strength and weakness for each child and, with use of proper software, specifies a number of potential program goals. Given that the CABS is the assessment tool used by two small option homes for children in the metropolitan Halifax area, the Committee felt that its use in the review process might be helpful to CTC staff, the Project Team planning for transition and future community based residential staff. The Committee reviewed the results of the assessments to verify that the final recommendations did not exceed reasonable expectations.

Summary of Recommendations

Major Areas of Concern

1. Safety and Security

- 1.1 *That standards for small option homes be developed by the Department of Community Services. These should include mandatory criteria for preservice training, ongoing staff development programs and the use of a personality profile instrument in staff selection. A routine, enforced system of inspection by the Department of Community Services, to ensure compliance with standards, is needed.*
- 1.2 *That the nature of Government's long term commitment for support of individuals currently in the CTCs be developed and articulated.*

2. Communication and Consistency

- 2.1 *That parent representatives participate in regular meetings with the Division Administrator and that the results of these meetings form a part of the regular evaluation of CTC administrators.*
- 2.2 *That management style, especially as reflected by communication with parents, be monitored by senior Department of Community Services officials and corrected as required.*
- 2.3 *That staff and administrators in the CTCs adhere to the requirements for reporting suspected child abuse as outlined by the Mandatory Reporting legislation and Departmental protocol.*
- 2.4 *That future investigations of suspected abuse be independent of anyone involved in the management of the CTCs.*
- 2.5 *That parent support groups be fostered at the CTCs and plans be encouraged for an ongoing parent network after the CTCs are closed. Such a group could ensure that all the children are receiving the best available services.*
- 2.6 *That announcements by the Department of Community Services or other government agencies that have a major impact on the CTCs be delivered to parents or guardians of residents of the CTCs before being made public.*

2.7 *That a formal process dealing with parent's concerns and complaints be created and publicized.*

3. The Nursing Unit at the Sydney CTC

- 3.1 That the provision of 24 hour nursing care continue for the children in the Nursing Unit. The contractual arrangement presently in place appears to be excellent.
- 3.2 That a parent of a child in the Nursing Unit and a representative of the Department of Community Services visit other service options for the "medically fragile" elsewhere in Canada to gain a first hand view of different ways of providing appropriate care for these children.
- 3.3 That consideration be given to placing all 7 children in one or two special group homes, thus retaining the identity of the unit and the integrity of the level of care while providing a more community style setting.
- 3.4 That placement of these children in an large institution or hospital not be considered as an option.
- 3.5 That, wherever the residential placement, more attention be given to community participation. Programming should be a non-medical responsibility assigned to a Program Coordinator and transportation suitable to the population should be available.

SPECIFIC ISSUES

1. General Care

- 1.1 That policies of the CTCs reflect principles of dignity and individualization and that specific practices contradicting these principles be prohibited. Examples include washrooms without doors, residents wearing the clothing of other residents, and strapping residents to toilet seats.
- 1.2 Given that the CTCs will close and that most residents will be living in community residences, programming which develops opportunities for choice and decision making needs to be undertaken.

2. Health Care

- 2.1 That a single physician for the entire institution is preferable even though the choice of a personal physician for each child seems attractive.
 - 2.2 That genital examination be a documented part of the annual physical examination.
 - 2.3 That the use of behaviour and mood altering medication be reviewed on a regular basis by the physician, staff and where appropriate, a consultant. Such medication should require a reorder at least every six months, accompanied by a notation indicating the reason for continuance.
 - 2.4 That the resuscitation status be clarified for each child in the nursing unit in Sydney and for all other residents with medical problems that have the potential for sudden deterioration (e.g. severe epilepsy).
 - 2.5 That consulting physicians be encouraged to see the children at the CTCs, rather than have the children brought to offices and clinics. This should allow greater input from the CTC staff. Parents should be encouraged to attend these consultations but a staff member who knows the child well should always be in attendance.
 - 2.6 That some medical appointments take place in doctors' offices in the community to foster integration.
 - 2.7 That the First Aid and Medical Manuals for both CTCs be reviewed, updated, and signed by the author. Several sections are outdated (e.g. the sections on epilepsy, fever, chickenpox, oral rehydration).
 - 2.8 That physiotherapy and occupational therapy services be contracted as required by the I.I.P.'s of the residents.
3. **Potential for Physical and Sexual Abuse**
- 3.1 That the CTC policy manual explicitly indicate both zero tolerance for abuse of any kind and an obligation to report any suspicion immediately.
 - 3.2 That staffing ratios must be such that individual staff members can be relieved for a period of time if they either feel or appear to be under great stress.

- 3.3 That the Department of Community Services consider the introduction of a personality screening device for new staff. While this may not apply to existing staff, it could be used in future to screen potential staff for CTCs and workers for new small option homes.
- 3.4 That present policies be continued so that at night there is always a mix of male and female staff and that personal care be carried out by same gender staff.
- 3.5 That regular visits from parents and/or advocates be encouraged through an "open door" policy.
- 3.6 That all staff receive training in the prevention of abuse. All staff should have completed this training by May 1, 1995.
- 3.7 That the Department of Community Services' "Physical Force Policy" be made congruent with the training provided to staff on Non-Violent Crisis Intervention.

4. Education

- 4.1 That the facilities used for educating CTC residents be properly staffed and equipped, as well as physically appropriate to the needs of the students and the demands of the program. The situation in Admiral Westphal School needs to be addressed as an urgent priority.
- 4.2 That the transportation system for CTC residents in Sydney be changed immediately, in order that travel time be minimized.
- 4.3 That all opportunities for inclusion with the regular school population be pursued, explored and taken advantage of, in both instructional and social contexts.
- 4.4 That staff at the CTCs become more proactive in assessing whether or not the programs and facilities are (a) appropriate to the needs of the child, (b) consistent with the goals of the plan in place at the CTC, and (c) oriented to the acquisition of skills which will assist the students as they move into community placements.

- 4.5. That there must be a closer relationship among parents, CTC staff and school personnel working together for the benefit of the residents. The exclusion of parents from decision making and the passively appreciative approach of the CTC staff may not be in the children's best interests.
- 4.6 That, as children move to community placements, parents, CTC staff, school board and Department of Education personnel do careful planning to ensure appropriate placement and programming in the least restrictive situation.
- 4.7 That older residents, no longer eligible for public school programs, be provided with vocational opportunities and/or Continuing Education programs in the community or at the CTCs.

5. Individual Program Planning

- 5.1 That the consultative services of a behavioral psychologist be utilized on a continuing basis to address the needs of residents. This individual should also assist staff in the development and implementation of programs for residents.
- 5.2 That a speech-language pathologist be readily available to assist in developing alternate ways for residents to communicate.
- 5.3 That the IPP program must be monitored and revised on a regular basis. Program reviews which involve parents and CTC staff should be carried out at least every four months.
- 5.4 That a goal of each IPP be the development of life skills necessary for the transition to community living. Individual programs must always include objective assessment procedures.
- 5.5 That an age appropriate bedtime be established for each resident.
- 5.6 That staff teams be designated to work with specific residents in order to enhance the level of consistency in their programs.

6. Involvement in Community Activities

- 6.1 That a staff person be assigned to plan the monthly schedule of events for CTC residents. This responsibility could be assigned on a rotating basis, so that all interested staff have an opportunity to provide leadership in this area.
- 6.2 That the children in the Sydney Nursing Unit be given an opportunity to participate in community outings. Staff with appropriate medical training would accompany these children.
- 6.3 That a larger, lift equipped bus be made available to each CTC.
- 6.4. That stronger links be established between CTC Administration, Parents and Municipal Recreation Departments in order to expand the participation of CTC residents in community activities.
- 6.5 That the CTC staff carry out a minimum of two outings with each resident every week. The outings should focus on the transition to community living (e. g. use of transit, shopping for personal needs, eating out in restaurants).
- 6.6 That the CTC staff assist residents in establishing age appropriate social interactions (e.g. Junior High dances, Girl Guides, Scouts).
- 6.7 That the residents be afforded regular opportunities to be supported in activities which they prefer or ones that their families feel they would enjoy. Residents should be exposed to a variety of activities in order to determine their likes or dislikes.

7. Social Networks and Supports

- 7.1 That a Community Advisory Committee be formed for each CTC. It would provide for Community representation, including neighbours and parents. Terms of Reference for the Committee might include developing strategies to promote social inclusion and recruitment of volunteers with the goal of supporting transition to community living.
- 7.2 That a higher priority be placed on individualized communication programs for the residents, including regular consultation with a speech-language pathologist.

- 7.3 That the staff and children share one cafeteria. Children need to be seated at tables in small groups, rather than individually, in order to promote socialization and a more typical mealtime routine.

8. Parental Involvement

- 8.1 That the CTC staff actively promote and support closer relationships between families and residents in the following ways:
- a. Development of a pleasant, private family room where children can visit with relatives;
 - b. CTC staff actively encourage home visits by accompanying the children to their homes, if families are receptive;
 - c. Residents, with the assistance of staff, give parents/family members homemade cards or gifts on special occasions.
- 8.2 That, where possible, parents be encouraged to contribute to their child's quality of life by becoming more involved in their child's out of center activities, (e. g. taking their children to community teen groups).
- 8.3 That a parent group be established in both CTCs and support be provided for parents to attend.

9. Advocacy

- 9.1 That the administration of the CTCs and their staff involve parents in all decisions which affect their child's well being. This would include IPP conferences, discussions of school opportunities, medical consultations, etc.
- 9.2 That social workers who are responsible for the supervision of those residents who are wards be made accountable for carrying out their mandate as outlined in the Manual of Procedure and in the Regulations to the Children and Family Services Act concerning visitation and reporting.
- 9.3 That the term "advocate" not be used in relation to counsellors' duties and be replaced by a more appropriate and less misleading designation.
- 9.4 That advocates be recruited from the community for children with infrequent visitors and for those with no legal guardians.

- 9.5 That the role of the independent advocate in supporting parents be affirmed and communicated.
- 9.6 That "crown advocacy" and a system of Advisory Committees on residential placement, as are mandated in the Province of Ontario be examined and possibly adapted to a Nova Scotian context.
- 9.7 That relevant training be provided to those social workers who are responsible for mentally handicapped children in care.

10. Respite

- 10.1 From the Minister's Advisory Committee on Services to Children with a Mental Handicap:
 - a. That a respite service be developed. Where it is determined by the family and the case manager that respite services are required, these must be tailored to individual families' needs;
 - b. That funding be made available to non-profit community based boards to establish respite services for short term care. These services must be available province wide.
- 10.2 That the Department's Project Team oversee the development of an improved respite service system with both in-home and out of home options.
- 10.3 That the Department widely and clearly communicate its policies and services in relation to respite to families of handicapped persons, professionals and the general public.

11. Administrative Support

- 11.1 That communication procedures and styles between the Dartmouth CTC and parents be reviewed and amended as required in order to ensure that it is responsive and open.
- 11.2 That the role and job description of Senior Counsellor be reviewed to ensure that they are expected and have the opportunity to provide leadership to line staff.

- 11.3 That the practice of having both Senior Administrators trained in nursing be reviewed. Several other fields of training have the potential to benefit CTC residents.
- 11.4 That computerized staff scheduling software be purchased immediately in order to allow the Assistant Superintendents to use their expertise for the direct benefit of residents.
- 11.5 That recording practices be reviewed and redundancy eliminated.
- 11.6 That regular comprehensive staff meetings be held to discuss the programming needs of residents.

12. Staffing Levels

- 12.1 That staffing levels be increased in both facilities to the enhanced level achieved in September of 1993 at the Dartmouth CTC. If this is deemed impossible due to fiscal restraint, then the Department of Community Services should accelerate the planning for closure and cease operations at both facilities at the earliest possible date.

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 - 13.7 That the Department of Community Services undertake the development of an intensive training program that will provide CTC staff with an orientation to community living, including value based workshops and visits to *community residences*. This program should begin by January 1995.

14. Funding

- 14.1 That the budget of the CTCs not be reduced by any arbitrary formula. The Committee did not recognize any more "efficient" ways of caring for these children. Virtually all suggestions for improvement call for greater staff numbers.
- 14.2 That a special interim budget be provided for the transition to community placement.
- 14.3 That a clear policy be developed by the Department of Community Services regarding supports for families whose children, now living at home, would have met the criteria for admission to the CTCs, prior to the admissions "freeze".

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with the child, a representative of the Department of Community Services and, if the parent desires, an advocate of their choice.

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- 15.7 That once the outline for community placement has been made for an individual, their IPP/IEP in the CTC and at school (where applicable) be altered to help prepare them for the transition.

APPENDICES

APPENDIX A

FRAMEWORK FOR REVIEW
OF
CHILDREN'S TRAINING CENTRES

AUGUST 1994

APPENDIX A**GENERAL CARE**

GOAL #1 TO HAVE ALL CTC RESIDENTS AFFORDED THE SAME LEVEL OF GENERAL CARE AND COMFORT THAT WOULD TYPICALLY BE FOUND IN A FUNCTIONAL FAMILY SETTING.

Evaluative Questions**EQUALITY**

- 1.1 Do residents get outside for recreational activities on a regular basis? (grounds of the Centre, in the community)

DIGNITY

- 1.2 Is the facility clean and odour free?
- 1.3 Do the residents' appearances reflect good grooming? (clean, hair groomed, appropriately attired, etc.)
- 1.4 Are disciplinary procedures appropriate and fair?
- 1.5 Are residents addressed in a respectful manner and tone?
- 1.6 Are the living quarters attractive and personalized?
- 1.7 How frequently do residents sustain injury? How severe are the injuries sustained? What is the most common source of injury? (e.g. other residents)
Do residents appear fearful of injury from other residents?
- 1.8 Do residents appear to feel safe and secure in the residence?
- 1.9 To what extent are residents afforded appropriate privacy in the residence?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 1.10 Can residents choose their own daily attire?
- 1.11 Do residents make food choices for meals and/or snacks?

APPENDIX A

- 1.12 Can residents choose their own leisure activities?
- 1.13 Do residents have input into the governance of the facility? What form does that take?

HEALTH CARE

GOAL #2 TO HAVE ALL CTC RESIDENTS HAVE ACCESS TO APPROPRIATE HEALTH SERVICES WHICH WOULD BE AT LEAST AS GOOD AS THOSE AVAILABLE TO CHILDREN OR YOUTH WITH SIMILAR HANDICAPPING CONDITIONS, LIVING IN A NON-INSTITUTIONAL SETTING IN THE SAME COMMUNITY.

Evaluative Questions

EQUALITY

- 2.1 Do all residents have regular health maintenance reviews with a family Physician?
- 2.2 Are "on call" services available for unexpected/emergency situations?
- 2.3 Are residents and/or their families able to choose a Physician in the community?

EQUITY

- 2.4 Are appropriate specialists services available?
- 2.5 Are medications properly stored and administered?
- 2.6 Is the responsible Physician clear for children entering the Centre for respite care?

DIGNITY

- 2.7 Is possible physical or sexual abuse treated as a health issue?

APPENDIX A**DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST**

- 2.8 Is the resuscitation status of each child in the nursing unit clearly understood?
- 2.9 Are medications used excessively for modification of behaviour?
- 2.10 To what extent are Parents involved in making decisions about their child's support and care?

POTENTIAL FOR PHYSICAL AND SEXUAL ABUSE

GOAL #3 TO ENSURE THAT THERE IS AS LITTLE RISK AS POSSIBLE THAT RESIDENTS WILL SUFFER FROM SEXUAL OR PHYSICAL ABUSE.

Evaluative Questions**EQUITY**

- 3.1 Are Staff trained to deal with potential abusive situations?
- 3.2 To what extent does Staff training include content on risk factors for abuse; recognizing signs of abuse; reporting impact of abuse on people's lives?
- 3.3 Is there a protocol that addresses investigation of abuse?

DIGNITY

- 3.4 Is there an attitude of zero tolerance to abuse?
- 3.5 Are Staffing levels sufficient to provide "peer" overview of Staff as they work?
- 3.6 Is there a mandatory reporting policy for any suspected abuse?
- 3.7 Is the atmosphere conducive to such reporting?
- 3.8 Is there a defined administrative procedure for the investigation of abuse?
- 3.9 Does each child have an outside advocate who visits often to emphasize the perception of each child as an important person?

APPENDIX A

- 3.10 Does the Physician consider issues of abuse during physical examinations?
- 3.11 Do Parents feel that their children are currently "safe" in the Centre?
- 3.12 Are Parents and other visitors free to come and go as they please in the CTC?

Information gathering questions:

- 3.13 Are the night Staff of opposite sex and who toilets whom?
- 3.14 Are new Staff screened for abusive potential?
- 3.15 Does personality screening detect potential abusers and, if so, how successfully?

EDUCATION

GOAL #4 TO HAVE ALL CTC RESIDENTS ACCESS THOSE EDUCATIONAL OPPORTUNITIES WHICH WOULD BE AVAILABLE TO CHILDREN OR YOUTH WITH SIMILAR HANDICAPPING CONDITIONS, LIVING IN A NON-INSTITUTIONAL SETTING IN THE SAME COMMUNITY.

Evaluative Questions

EQUALITY

- 4.1 Are school programs delivered in appropriate facilities?
- 4.2 Are travel arrangements efficient and comfortable?

EQUITY

- 4.3 Are students being educated in the least restrictive environment available?
- 4.4 Are program offerings equivalent to those provided to other children who live in the community?
- 4.5 In which ways are CTC Staff involved with the residents school program?

DIGNITY

APPENDIX A

- 4.6 To what extent do individual's plans emphasize their strengths, capacities and their potential?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 4.7 To what extent do Parents or Legitimate Advocates have input into educational programming?
- 4.8 To what extent is there a correlation between the IEP at the school and the IPP in the residence?
- 4.9 Are there aspects of the school program which prepare the student for community living?
- 4.10 What is the degree of cooperation between school personnel and CTC Staff?

Information gathering questions:

- 4.11 How many children from the CTC who are school aged attend public school?
- 4.12 Do they have an individual education plan in place?
- 4.13 Does the program meet statutory requirements under the Education Act?

INDIVIDUAL PROGRAM PLANNING

GOAL #5 TO HAVE AN INDIVIDUAL PROGRAM PLAN DEVELOPED BASED ON THE CHILD'S ABILITY, AND FOR THAT PROGRAM TO BE UPDATED AND MONITORED ON A REGULAR BASIS.

Evaluative Questions

EQUITY

- 5.1 Are programs being delivered consistently by one person or by different Staff members? Who delivers the program?

APPENDIX A

- 5.2 Is the need for external resources identified and actively sought out when a particular or unresolved problem surfaces?
- 5.3 Are physio-therapists, occupational therapists, psychologists, psychiatrists, speech therapists easily accessed and consulted regularly if their services are required?

DIGNITY

- 5.4 If Parents disagree with the program plan developed for their child, are their opinions respected and is the program altered accordingly?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 5.5 Are the goals established in the IPP similar to those stated on the IEP?
- 5.6 Are the goals established for each resident realistic?
- 5.7 Does each child's Individual Program Plan reflect their developmental ability and special interests?
- 5.8 Do the programs set up for each resident allow children/residents to experience making choices and learn decision making?
- 5.9 Is there a daily routine established for each resident?
- 5.10 Is there documentation on each resident to establish that a program is in place for each resident?
- 5.11 Are Parents asked for their input in regard to programming and are they given a copy of their child's program?

Information gathering questions:

- 5.12 Does an IPP program currently exist for every resident in the CTC?
- 5.13 Who is responsible for developing individual programs for CTC residents?
- 5.14 How often is the IPP program reviewed and revised?
- 5.15 Who monitors program changes and ensures changes to such programs are implemented?

APPENDIX A

- 5.16 How intensive is the program?
- 5.17 Who delivers the program?
- 5.18 How is the resident's current level of functioning and potential assessed?

INVOLVEMENT IN COMMUNITY ACTIVITIES

GOAL #6 CTC RESIDENTS SHOULD BE VISIBLE IN THE COMMUNITY AND SHOULD HAVE EQUAL ACCESS AND EQUAL OPPORTUNITIES TO PARTICIPATE IN COMMUNITY EVENTS AND ACTIVITIES.

Evaluative Questions**EQUALITY**

- 6.1 Are the children from the CTC visible in the community?
- 6.2 Do CTC Staff work towards and believe in community integration?
- 6.3 To what extent do individuals have opportunities and support to participate in community activities according to their wishes, preferences and abilities?

EQUITY

- 6.4 Is it possible to expand opportunities for CTC children to participate in community activities given the current Staff/resident ratio?
- 6.5 How do the children from the CTC travel to outings in the community?
- 6.6 Does the transportation utilized by the CTC address the physical needs of the residents?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 6.7 Are Parents invited to attend community outings with their children?
- 6.8 Do family members have any input into what type of community activities their children are involved in?

APPENDIX A

6.9 Are Parents satisfied with the level of community involvement or do they feel their children should leave the Centre more often?

Information gathering questions:

6.10 How many children participate in community outings?

6.11 What type of community activities/leisure experiences are the children from the CTC involved in?

6.12 Are these activities age and developmental stage appropriate? Do these activities provide opportunities for the residents of the CTC to interact socially, with peers of the same chronological age?

6.13 Are summer programs/camping experiences available to the CTC population? How many of the CTC children have participated in summer recreation programs or have attended summer camps?

6.14 Are respite children participating in community activities and if so how do these activities compare with what they do when they are at home with their families?

6.15 How many Staff are required for community outings? Are there sufficient Staff for regular community outings?

6.16 Who is responsible for scheduling community outings?

6.17 How many residents can be accommodated by transportation provided by the CTC at any given time?

SOCIAL NETWORKS AND SUPPORT

GOAL #7 TO HAVE SOCIAL AND PEER RELATIONSHIPS SIMILAR TO OTHER SCHOOL AGED CHILDREN AND YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES LIVING IN THE COMMUNITY.

Evaluative Questions

EQUALITY

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7.1 To what extent do children/residents enjoy the involvement of relationships with non-paid individuals and a network of core family and friends?

EQUITY

7.2 Does the CTC actively foster the development of personal networks?

Information gathering questions:

7.3 Do the children and young adults have any friends that visit with them that are not family members or Staff?

7.4 Do the children and young adults go out into the community to social groups or events external to the CTC?

7.5 Do the children or young adults have friendships with other children in the facility? Are preferences acknowledged and supported in any way?

7.6 Do the children exchange gifts at Christmas or have birthday parties with children whose company they seem to prefer?

7.7 Do the Staff and children know their neighbours and are there any opportunities for interaction?

7.8 Are social and communication skills encouraged and developed through the children's IPP's and IEP's or through normal rhythms of the day?

7.9 Are volunteers utilized at the Centres and if so, how and what has been the experience with them?

PARENTAL INVOLVEMENT

GOAL #8 FOR ALL PARENTS/ADVOCATES TO HAVE ON-GOING PARTICIPATION AND INVOLVEMENT IN THE DECISIONS AFFECTING THEIR CHILDREN

Evaluative Questions

EQUITY

8.1 Does the CTC assist in arranging Parent/Family supports?

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DIGNITY

8.2 Are Parents/Advocates encouraged to be involved in maintaining relationships with their children?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

8.3 Do Parents/Advocates have input into the IPP/IEP developed for their child?

8.4 Are family members invited to attend social gatherings at the CTC which in turn foster and reinforce the sense of family?

8.5 Are children assisted and supported in maintaining contact with their Parents? i.e. making cards/giving gifts on appropriate occasions.

Information gathering questions:

8.6 How many Parents/Extended Family members/Advocates show an active interest and are actively involved in decisions concerning their children?

8.7 How many children visit their Parents at home and how often does this occur?

8.8 Is there a Parent support group for each CTC? Who organizes this group? Is the Parent support group cohesive and active? How often does each group meet? Do C.A.S (social workers) attend these meetings on behalf of those children who are wards of the court? How involved are CTC Staff/Administrators in these meetings? How receptive/responsive are Staff/Administrators to suggestions made by the Parent group?

ADVOCACY

GOAL #9 THAT RESIDENTS OF THE CTC WOULD HAVE THEIR BEST INTERESTS PROMOTED IN ALL ASPECTS OF THEIR CARE, COMFORT AND TRAINING BY RESPONSIBLE ADVOCATES, IRRESPECTIVE OF WHETHER OR NOT THEY HAVE PARENTS TO DO SO.

APPENDIX A**Evaluative Questions****DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST**

- 9.1 When there are no Parents or when Parents abdicate, who assumes the advocacy role?
- 9.2 At this time are Legal Advocates (e.g. social workers) discharging their responsibilities in an appropriate and responsible manner?
- 9.3 To what degree are such Legal Advocates perceived to be knowledgeable of the residents and their needs?
- 9.4 How active are these Advocates in the IPP planning process?
- 9.5 Are they seen as surrogate Parents or simply as a necessary legal entity?
- 9.6 What are the checks and balances in place to see that all residents are represented when significant decisions are made?
- 9.7 To what extent is independent advocacy in place?

Information gathering questions:

- 9.8 When there are no Parents or uninvolved Parents, who is informed in matters of illness, accident, misfortune, or indeed, death?
- 9.9 How formalized is that role?

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RESPITE

GOAL #10 TO PROVIDE AN OPTION FOR OUT OF HOME RESPITE CARE FOR FAMILIES.

Evaluative Questions:

EQUALITY

- 10.1 Why do families use the Centres for respite?
- 10.2 What effect does the policy of zero admission to CTCs have on respite use and availability of services?

EQUITY

- 10.3 What is the level of parental satisfaction with respite care at the CTCs?
- 10.4 What is the effect of respite care usage on staff and the children who are permanent residents of the CTCs?
- 10.5 What options are currently being utilized by families who have children who were effected by the closures of Pictou and Digby CTCs? What is the level of satisfaction of parents who are now using other respite options and what changes have they experienced?
- 10.6 What assistance do families receive in finding alternate respite arrangements if the CTC is not available?
- 10.7 Are policies and respite options written and clearly understood by families?

DIGNITY

- 10.8 What is the effect on families if they are not able to access the Centres for respite?

Information gathering questions:

- 10.9 What are the criteria to qualify for respite use?

APPENDIX A

- 10.10 How frequently are the CTCs being utilized?
- 10.11 What is the ratio of long term versus short term respite use?
- 10.12 How is respite funded?

ADMINISTRATIVE SUPPORT**GOAL #11 TO HAVE EFFECTIVE ADMINISTRATIVE PRACTICES IN PLACE WHICH ENHANCE SERVICE DELIVERY TO RESIDENTS.****Evaluative Questions****EQUITY**

- 11.1 Do Administrative Staff know their Staff well and are they in regular contact with all of the Staff?
- 11.2 Are there administrative tasks which are too time consuming and could better be dealt with by computer or by clerical Staff?
- 11.3 Are there times of the day or week when Administrative Staff are not available? (e.g. Staff scheduling)

DIGNITY

- 11.4 Do Administrative Staff know the residents well?
- 11.5 Do Administrators have regular contact with residents?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 11.6 How are concerns raised by a Staff person or a Parent/legitimate advocate (a) acknowledged and (b) responded to? In what time frame?

Information gathering questions:

- 11.7 Are there clear lines of communication and authority within the Centre?
- 11.8 Do Centre Administrators collaborate with other agencies regularly?

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- 11.9 What sort of relationship exists between the Centre Administration and "Head Office" Administrators?
- 11.10 Who feels supported by whom?
- 11.11 What administrative areas appear to be strengths?
- 11.12 What administrative areas appear weak?
- 11.13 Do Centre Administrators evaluate their needs regularly and pursue needed resources assertively?
- 11.14 Who carries out performance evaluations/reviews with Superintendents? How often? With what sort of follow up and accountability measures?

STAFFING LEVELS

GOAL #12 TO HAVE A CONSISTENT STAFFING LEVEL IN THE CTC's THAT WILL ENABLE RESIDENTS TO EXPERIENCE OPPORTUNITIES AND QUALITY OF LIFE OUTCOMES SIMILAR TO OR BETTER THAN EQUIVALENT CHILDREN LIVING IN THE COMMUNITY.

Evaluative Questions**DIGNITY**

- 12.1 What is the relationship between Staffing levels and incidents reports? (no. of incidents between children and between children and Staff)

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 12.2 How are consistent caretakers provided for each child?
- 12.3 Do existing Staff levels enable IPP's to be carried out effectively and consistently?
- 12.4 Is there a relationship between reduced Staffing levels and the frequency of sick time used by Staff? Does reduced Staffing effect Staff morale and if so, how?

APPENDIX A

- 12.5 Does the existing level of Staff allow children personal freedom and opportunity to make choices about their daily activities?

Information gathering questions:

- 12.6 What is the ratio of casual Staff to permanent Staff in the facility? Per shift? How do the two groups of Staff relate to one another? Do they work cooperatively to accomplish the same goals?
- 12.7 What was the rate of turn-over in Staff positions over the past two years.
- 12.8 How many times have Administrative Staff at the CTC's requested replacing Staff or hiring additional Staff and what has been the response?
- 12.9 How long does it take to replace Staff who leave and how does this effect the Staffing pattern at CTC's?
- 12.10 How frequently have Staffing levels been increased or decreased in the past year and why? What has been the impact of changes?
- 12.11 How frequently and for what period of time do children receive one to one attention?
- 12.12 How do Staff ratios at the CTC's compare to those in small options?

STAFF TRAINING

GOAL #13 TO ENSURE ALL STAFF AT THE CTC's HAVE QUALIFICATIONS AND TRAINING NEEDED TO PROVIDE A QUALITY SERVICE TO RESIDENTS.

Evaluative Questions**EQUITY**

- 13.1 Does the facility have an orientation program for new employees?
- 13.2 Does the orientation program address basic knowledge and skills required to begin to perform direct care tasks?

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- 13.3 What evidence exists that all Staff have completed orientation within the first few months of employment?
- 13.4 Do casual Staff receive the same kind of orientation as permanent Staff?
- 13.5 Does an annual plan exist for in-service training and is it specific to the needs of the specific facility?
- 13.6 Are there quality assurance measures in place to ensure Staff receive in-service training?
- 13.7 What evidence exists that plans are carried through?
- 13.8 Are the training needs of Staff assessed regularly and how is this done?
- 13.9 If Staff do not have pre-service academic training, are efforts made to assist these Staff to upgrade their qualifications?
- 13.10 Are training plans based on core competencies necessary for residential Staff?
- 13.11 Does training address philosophy and values that are current in the field of developmental disability?
- 13.12 Are training outcomes assessed? Does training result in changes in Staff performance leading to improved quality of life for the residents? How are changes measured and by whom?
- 13.13 Are Staff themselves involved in the design, implementation and evaluation of training activities?
- 13.14 Do external professionals provide consultation for specific children that takes the form of on the job training?
- 13.15 Given the problem of replacing Staff on shifts while they attend training; are any innovative solutions to this dilemma being attempted and with what results?
- 13.16 Have managers and supervisors received training specific to their needs?
- 13.17 Given the plan to close facilities in the future, are Staff being retrained and reoriented towards employment in the community?

APPENDIX A**Information gathering questions:**

- 13.18 What percentage of employees have pre-service training attained in an academic setting related to their positions?
- 13.19 How often has the facility provided practicum experiences for students from various programs?
- 13.20 How many Staff attended external training opportunities sponsored by advocacy organizations, colleges or other agencies in the past year?

FUNDING

GOAL #14 TO ENSURE THAT THE BUDGETS OF THE CTC ARE ADEQUATE TO ACHIEVE THE GOALS NOTED IN THIS DOCUMENT.

Evaluative Questions**EQUALITY**

- 14.1 Do the funding levels at the CTC's ensure that children will receive supports and services according to individual need?

EQUITY

- 14.2 *Has the increased Staffing in Dartmouth improved the program? If so in what ways?*
- 14.3 What are the consequences of decreasing the number of Staff back towards the former levels for immediate programming and longer term outplacement?
- 14.4 What are the benefits to justify an increase in Staff in Sydney?
- 14.5 Would changes in the physical equipment available make a difference to programming in Dartmouth? Sydney?
- 14.6 Are additional funds needed for the transition?
- 14.7 Does the current Staff ratio compare reasonably to external standards?

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- 14.8 Why was more money put into the Dartmouth Centre?
- 14.9 How can the current level of funding be protected in the current fiscal restraint atmosphere?

TRANSITION PLANNING AND COMMUNITY PLACEMENT OPTIONS

GOAL #15 TO HAVE A TRANSITION PROCESS WHICH OFFERS FAMILIES CHOICE AND SELF-DETERMINATION IN SELECTING FROM A RANGE OF COMMUNITY OPTIONS, EACH OFFERING AN ENHANCED QUALITY OF LIFE TO THE RESIDENTS WHO MUST MOVE FROM THE CTCS.

THREE OPTIONS

- 1) **HOME WITH NATURAL FAMILY**
with supports such as respite, special equipment and renovations to house, Parent support and skill training.
- 2) **ASSOCIATE FAMILY {Specialized foster home}**
with services including respite, special equipment and renovations to house, opportunity for on-going training for associate families. Ideally close association with the natural family with frequent visiting.
- 3) **SMALL OPTION HOMES**
Licensed small option homes with a high Staff ratio and no more than three children in the home. Ideally close to the natural family to promote frequent visiting.

Evaluative Questions**EQUALITY**

- 15.1 Is there a continuum of high quality service options available to children and families?
- 15.2 Is the system flexible enough to develop options that are individually tailored to the needs of each child?

EQUITY

APPENDIX A

- 15.3 Is the option of home placement explored with families and are they made aware of services and funding that are available or that could be created to support keeping the child at home?
- 15.4 Once placed, are children able to access required specialists for consultation and service provision if needed? (speech therapists, neurologists, physiotherapists, psychologists)

DIGNITY

- 15.5 How will the concept of "children" be preserved?

DECISIONS ARE MADE IN INDIVIDUAL'S BEST INTEREST

- 15.6 How will Parents be involved?
- 15.7 Are a variety of options for each child to be considered?
- 15.8 How will very long term residents of the Centre be dealt with and do they present special issues?
- 15.9 Will each child's IPP and I.E.P be altered to take into account the type of placement contemplated?
- 15.10 What structure might be envisioned for the nursing unit children?
- 15.11 What supports would be placed for Parents of the children?
- 15.12 Are families provided with information about the strengths and weaknesses of options so they can make informed choices?
- 15.13 Are placements made close to family members, if the family wishes this?
- 15.14 Are Parents meaningfully involved in planning for their son's and daughter's futures?
- 15.15 Is individual compatibility considered when grouping children for small option placement?
- 15.16 Are efforts made to promote collaboration and partnership with families, CTC Staff, Municipalities, School Boards and other community groups?

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15.17 Are there contingency plans if living arrangements turn out to be unsatisfactory?
Can placements be renegotiated and a more suitable placement made?

Information gathering questions:

15.18 Are guidelines or standards in place for small option homes and are there mechanisms in place to monitor placements?

15.19 Which options have been most frequently chosen by families and which, if any, have proven to be best for children who have moved from Digby, Pictou, and Dartmouth CTCs?

15.20 Are children who are considered "medically fragile" able to be cared for in the community? What evidence exists to support or detract from this concept? What is required to make community placements for this specific group of children successful?

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APPENDIX B**FOLLOW-UP SURVEY OF PARENTS AND GUARDIANS OF CHILDREN WHO
HAVE MOVED FROM CTCs SINCE 1991**

Method

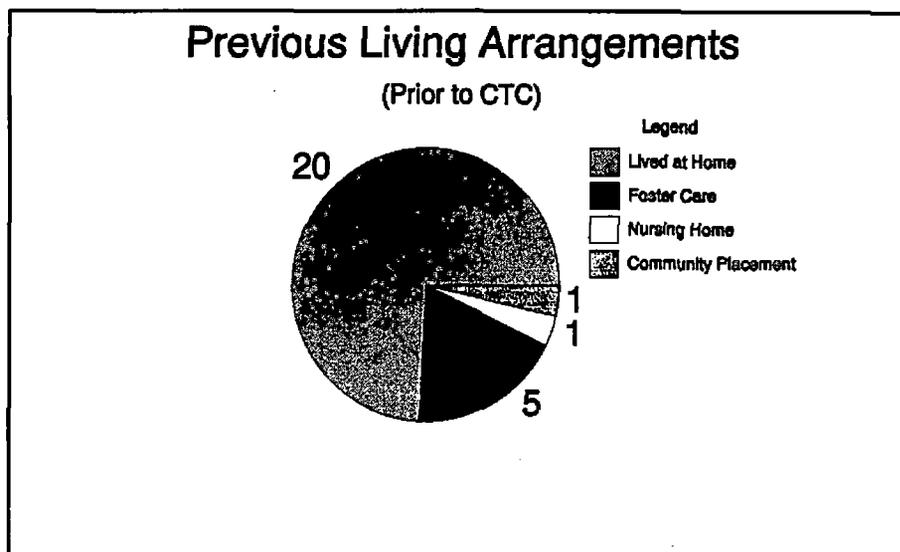
In July 1994, a letter explaining the survey was sent to the thirty five parents and two responsible Social Workers, who had children younger than 21 years of age when they moved from the Dartmouth, Pictou or Digby CTCs, following the 1991 announcement by the Department of Community Services that the Centres would close. Subsequently, a total of twenty seven persons were interviewed using a structured format developed by the Review Committee and its consultants. Twenty-four contacts were by telephone and three were personal interviews.

Additionally, telephone interviews were carried out with seven of the eight families who had made use of the Pictou Centre respite services, prior to its closure.

Previous and Current Living Arrangements

Of the children who resided in CTCs on a full time basis, 11 resided at the Pictou CTC, five in Digby and 11 in Dartmouth. Difficulty contacting families accounts for the low number of interviews with Digby parents.

Before moving to the CTC, 20 children lived at home, five in foster care, one in a nursing home and one in a community residential placement in another province. The average length of stay at a CTC was 6 years (range 2 months - 15 years).

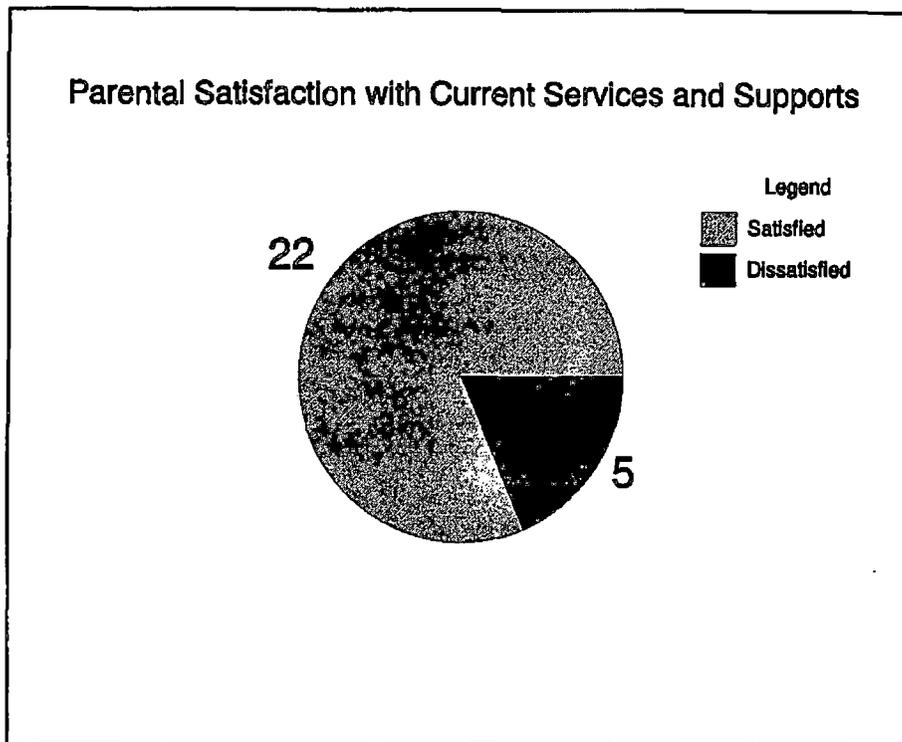
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Currently, 21 of the children live in Small Option Homes, two in Developmental residences, one at home, one in foster care, one at the King's County Rehabilitation Centre, and one at the Dartmouth CTC.

Current Services and Supports***1. Summary***

Of the 27 individuals interviewed, twenty-two were very satisfied with the current services and supports for their children. They expressed similar satisfaction with the planning process for the moves of their children from the CTC.

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2. Education

Currently 16 children attend school on a full time basis. Two parents reported that their children attend school for 1.5 hours per day. One child receives schooling where she lives. Three respondents indicated, that to their knowledge, their children received no formal schooling. Two of the children who currently attend school, spend a day or less each week at a sheltered workshop.

The majority of parents or guardians were very satisfied with their children's schooling arrangements. They felt that their children were receiving "the best education they could". Four parents questioned the capacity of the school system to satisfactorily

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incorporate mentally and physically challenged children in either segregated or integrated classrooms. One parent noted:

"Even teachers need to be educated a bit more. Teachers are often unfamiliar with handicapped children".

3. Sheltered Workshop Programs

Three children attend a full time sheltered workshop program. Two of their parents were very pleased with this arrangement. One of these parents noted:

"There should be some transition from school to workshop. Our child did a transition program a couple of days a week. It really helped. We had to take the initiative though - it wasn't offered. They should implement it."

The parent dissatisfied with the workshop program summarized her concerns:

"I didn't really want my child in a sheltered workshop, but there was nothing else after she left school. It was noisy with large numbers - my child would just not be suited to a 9 to 5 job."

4. Financial support

Because their children are not living at home, no parent of a full time CTC resident is currently receiving financial assistance for child care. Funding sources varied for technical aids or devices required by twelve of the children. Only two parents said they pay for all their children's aids and devices, one of these parents noted that this was by choice, the other noted he was not satisfied with this arrangement. Two parents said they made a financial contribution and the facility where their children lives pays for the rest. Two parents noted that their insurance companies pay for the majority of their children's devices, with either themselves or the Department of Community Services paying the balance.

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For the remaining parents, funds came entirely from the Department of Community Services, service organizations, Sir Frederick Fraser School for the Blind, or the School for the Hearing Impaired.

THE TRANSITION PROCESS***Planning at the CTC prior to the move***

Much of the survey dealt with the transition process from the CTC to the community. Parents were asked about which staff were involved, what they did and how helpful they were.

1. CTC Staff

Eleven of the twenty-seven families felt that the staff of the CTC were very helpful during the planning process for the move away from the CTC. They noted helpful discussion of the various options and a supportive, reassuring approach.

One parent stated:

"She (the superintendent) and staff went to the Small Option Home to see if it was suitable for my child. They were very open and willing to talk to me. They also gave us the option of letting him go back to the CTC if it didn't work out in a few weeks or months to find a more suitable placement. There was no more they could do for us."

Fifteen parents stated that the CTC staff were not directly involved in planning the move. Three of these parents had abruptly removed their children from the CTC without an opportunity for planning. Other parents noted that the CTC staff did not assist in outlining the housing options for their children.

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2. Administrative and In-Home Support Staff

Twenty one families acknowledged the help of the Department of Community Services' staff who did not work directly at the CTCs. A number of individuals from the Administrative Staff of Services for the Mentally Handicapped, Department of Community Services, were praised for arranging funding, overseeing the financial strategy and dealing with Town Councils.

Five families were not satisfied with the role of the Department of Community Services in the move of their children. Seven families felt that the process was too long. Two of these children needed temporary placement because the CTC closed before they could move to their new facility. Criticisms included:

"Community Service workers could have gotten to know our family and daughter better, to better understand and know our needs".

"They should have brought in some competent people who had gone through the process before, to work with parents from the very beginning".

"We would like guarantees the next time, that there won't be any road blocks. We don't always want to go right to the Minister. There should be a system of services. We shouldn't have to go to the top every time".

Nearly all of these families cited the In-Home Support workers as the most helpful and resourceful. These workers set up committees to review each child's needs and then accompanied parents on visits to Small Option Homes or other facilities, answered questions and provided updates about the process. The pivotal role of these workers is illustrated by several quotes from parents:

"They (the In-Home Support Workers) worked very hard in trying to set something up for us. They were very easy to reach through it all".

"Our support worker approached us about a small option. She did everything for us, had the meetings, etc. We only really worked with her. She was so very supportive, she couldn't have done anything more!".

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"They kept me informed of the whole process. I always knew what was going on".

3. Parental Involvement

Most parents were satisfied with their involvement in the planning process for the transition of their children from the CTC to the community. Parents acknowledged their involvement in numerous meetings with In-Home Support workers and Administrative Staff from the Department of Community Services. Families helped choose a house for their children, discussed options for living arrangements, helped to hire small option home staff and assisted in developing individual programs.

4. Others Involved in the Planning Process

Many others were involved in the planning process. These included supervisors of Small Option Homes, and representatives of Regional Residential Services Society, the Canadian Association for Community Living, the Queen's Association for the Mentally Disabled, the Green Door Society, the Dartmouth Parks and Recreation program, the Parent Support Network of Nova Scotia and various Municipal workers. These people played many roles including being "supportive", providing "a shoulder to cry on", organizing meetings, securing living arrangements and hiring staff.

5. Supports for Parents

Most parents noted reasonable assistance in planning for the move from the CTC; however few noted "organized" emotional supports for themselves. They relied on family and friends, although the assistance and understanding of the In-Home Support workers was often acknowledged.

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Early in the planning process, some parents were very anxious about the future for their children. One father noted:

" We had no idea where our son was going to go after the CTC. It was a frightening feeling".

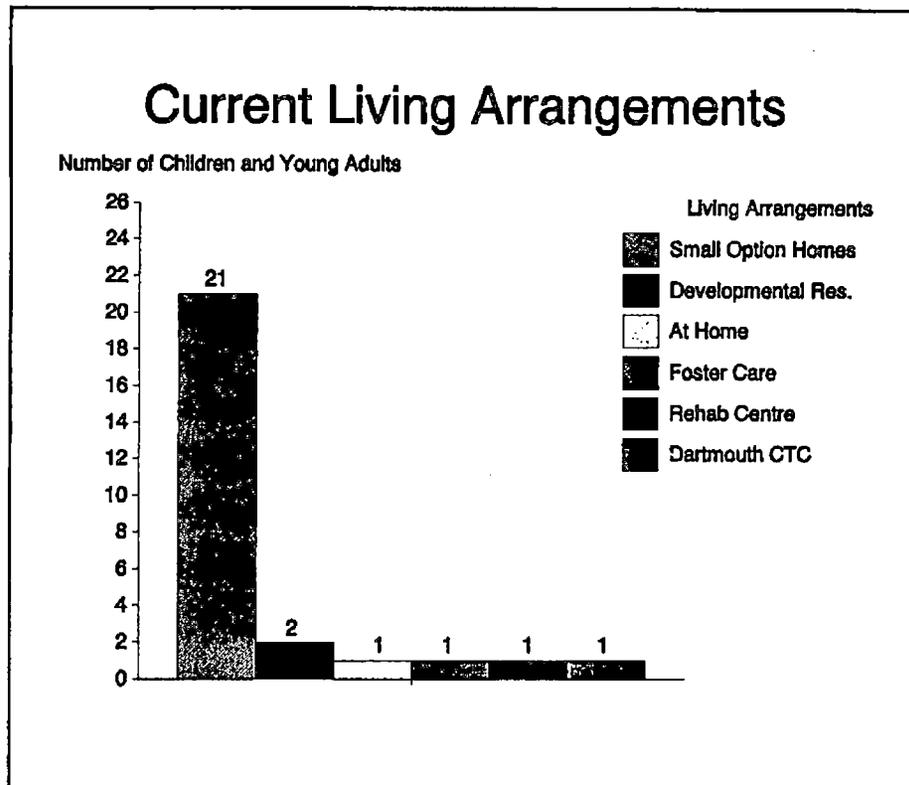
Many parents attended a number of parent meetings at the CTC but few acknowledged belonging to a "parent support group". Three parents are members of the Parent Support Network of Nova Scotia. Five parents from outside the Metro area stated that they would have joined a parent support group if it were not for distance problems.

Current Living Arrangements

A number of parents indicated that the ideal placement for their children would have been at home; however, they hastened to note that this still would be impossible. They felt that their children's placements at the CTC were very secure. All but three parents felt that their children had been safe and well looked after at the CTCs. One mother said,

"Our family could never say anything about all the care and attention our child received at the CTC. They were wonderful to him."

As noted earlier, 21 of the children now live in Small Option Homes, two in Developmental residences, one at home, one in foster care, one at the Kings County Rehabilitation Centre, and one at the Dartmouth CTC.

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Most parents stated that their children's current placements are close to "ideal". Most felt that placements are stable, secure and better than they had expected. Of parents with children in small option homes, 20 of 21 are very satisfied with the living arrangements.

Nearly all parents concluded that life was "better" now for their children than when they were at the CTC. Some reasons were:

"My son gets a lot of peer exposure at his new home. The counsellors are a mixture of young males and females at the Small Option Home. Even though the younger people don't have the experience as many of the counsellors from the CTC, they have energy to go rollerblading, ice skating, etc".

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"It is like her being at home. She is in her home community, her school with her own friends".

"The Small Option Homes are more of a home setting, more comfortable ... with more personal attention".

Decision Making

Most parents reported that decisions were made by consensus about their children's living arrangements, education, health care and community activities. Consensus was achieved between parents, In-Home Support Workers, Administrative Staff of the Department of Community Services and others. Only a small number stated that they made all the decisions themselves or were not involved at all in decisions. Nearly all parents seemed very satisfied with the decisions made and their roles in the decision making process.

Decisions about staffing in small option homes are of concern to some parents. Few parents were given the opportunity to interview and participate in selection of these staff. One parent noted,

"I would like to know when they are hiring or letting go staff and to be introduced to new staff. Now it's almost as if we are strangers in someone else's house when we go there."

Advice for other parents approaching the same transition process

Parents made several recommendations for future parents facing similar decisions. The recommendations are well illustrated by three quotes.

"Patience is really important. Parents need to deal with change along the way".

"Parents need to be aware of the options out there, other parents who have already went through this should be available to give support to new parents".

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"Parents need a lot of support. It's not until the kids leave the CTC and go into a Small Option that you realize it is so much better. Parents should go see the Small Options".

Respite

Seven families who used the Pictou CTC for respite care for their children were interviewed by telephone. One of these families now uses the Dartmouth CTC for respite. Information about the six who use other arrangements is discussed below.

Most families used respite services at the Pictou CTC for one to two weekends per month and during a summer vacation of at least one week, but no more than a month. All parents felt that their children were safe and well cared for at the CTC.

Currently all families have an alternate respite program. Two use an Adult Residential Centre and find it to be equivalent to the CTC. Two have respite care in their own homes - a hired respite worker comes to their homes for about 20 hours per week in the winter and for extended hours during the summer. For the other two, a family relative cares for the children in a parents' home a few hours each week, one weekend a month and during a summer vacation.

All families receive financial assistance for respite care. In finding new respite services, parents were assisted by the CTC who offered names of trained workers and by In-Home Support staff who assisted in the choice or contacting other agencies and facilities. Again, the In-Home Support workers were very helpful. One parent felt that she had not been sufficiently assisted. She said,

"There should be an organized way to find respite care. It is hard doing it on your own, mostly".

When asked if the change in respite arrangements had any impact on their children, three parents noted no difference, one noted a positive change and two a negative impact.

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Negative comments included:

"It was a lot easier on us when we could bring him into the CTC. We have to leave our own home to get a break now".

"Our son finds it more boring now with someone coming into our home. At the CTC, they kept him busy".

"If we can't get respite when we need it; we don't go. At the CTC it wasn't an issue. They would take our daughter at an instant, if needed, but my sister has two children and it's not always possible in a minor emergency to get respite care."

A positive comment was:

"It's had a positive impact on our son. He can be at home now for respite care. It saves hassle for moving things for his respite care, such as his bath chair, etc ... in fact, our respite care in the last two years has increased because of the closure of the CTC."

Overall, of the six families, one parent felt very satisfied with the current respite services, four noted the same degree of satisfaction as in the past, although the style of respite care is different. One parent felt that the CTC had been a better respite provider.

No parent had considered permanent placement of their child because of the change in respite care. Two parents noted considerable help from a parent support group through the transition period and at present. Four did not feel the need for a parent support group at present.

Conclusion

Overall, the majority of parents interviewed seemed satisfied with the services and supports they currently receive. Parents did express concerns over not knowing where their children would live after leaving the CTC and not always knowing the options available to them. Most parents also felt that their children were well looked after while living at the CTC, and in their current living arrangements. Families seemed especially

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enthusiastic about the Small Option Homes and the level of personal care and attention given to their children there.

When discussing respite needs, families expressed strong feelings over the closure of the CTCs and their difficulty finding new respite care for their children. A number of parents felt it was mostly up to them to initiate new respite plans.

All parents who were contacted, were eager to discuss their children's needs, the services they use, as well as, their general satisfaction with their son's or daughter's move from the Children's Training Centre.

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APPENDIX C***Critique of the Background Report of the Roeher Institute***

The Roeher Institute prepared a Background Report which was forwarded via fax on August 23, 1994 and received by mail on August 31, 1994 by the Committee. (Appendix D) It was agreed, in discussion between the Committee Chair and the Director of the Roeher Institute, that the Background Report received at that time would be an appendix to the Review Committee's Report.

Although discussions with the representatives of the Roeher Institute were helpful to the Committee during the review, their report has a tone and direction that is not always shared by the Committee.

The Roeher background report is highly dependent on interviews offered by two or three families, mainly former users of the Dartmouth CTC. These families were very critical of the CTC, its staff and the Department of Community Services. Most quotes in the report come from these few families but are not referenced as such. This gives the reader an erroneous sense that the concerns were expressed by a wider group of parents. Most parents of present CTC residents categorically stated to the Review Committee, with certainty, that they did not have concerns of a similar nature.

The Committee had the opportunity to interview a much wider number of parents both in Dartmouth and Sydney than did the Roeher consultants. Most parents reported positive experiences for their children. This very powerful and positive endorsement of the CTC system is not reflected in the Roeher report.

The reader should, therefore, keep clearly in mind that the Roeher report suffers from serious "sampling bias". The conclusions do not apply to the vast majority of children at the CTCs, nor do they reflect the views of most parents.

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In addition, the Roeher background report seeks policy changes that are beyond the Terms of Reference given to the Committee. These policies are amongst the expressed goals of the Roeher Institute but have little direct impact on the current functioning and pending closure of the Dartmouth and Sydney CTCs.

The Committee has reviewed the Roeher background report carefully and makes the following detailed comments/observations:

Introduction

Page 2 - The Roeher group did not recommend "dropping the fifth element" (i.e. "coordination among and within government departments in order to achieve quality of life") as a principle to guide the review. The Committee decided that this theme was well beyond the mandate of the review.

The Family Support Network of Nova Scotia (formerly the CTC Support Group) has a limited number of members whose children were previously residents of the CTC's. There are several members who do not have children with disabilities or whose children have never accessed the services of a CTC.

Page 3 - The statement "undoubtedly there are some parents that vary from those presented in this report" is misleading. Most parents had a very different perspective. This is well illustrated by our survey of parents of children who moved from Pictou, Digby and Dartmouth CTCs prior to 1991.

Page 5 - The definition of Equality is broader than that used by the Committee.

Page 5 - Of course the CTC is not a "home". However, many parents in Sydney expressed exactly the opposite opinion. They viewed the child's home as the CTC and viewed it as having all the attributions of a real "home".

Page 6 - While it is true that community involvement for CTC residents is limited, the statement that "children are not perceived by the community to be equal with others" is not based on any information gathered in this review. In addition, this is an issue far beyond the purview of this review and reflects attitudes and issues in society in general.

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Page 7 - The contention that education may have been limited for those "confined" to the CTC is misleading. All children eligible by age, with the exception of Nursing Unit residents, do in fact attend school. The comment relates to "sick days".

The definition of equality was not the one used by the Committee. In general, the Committee viewed equality, for CTC residents, as having access to activities, services and experiences at least equivalent to similar individuals in Nova Scotia who are living in the community.

Page 8 - The reasons for previous placements in the CTCs were considered beyond the scope of this review. The focus of the review is to improve the present situation for residents of the CTCs and to make suggestions for transition.

"Still being resolved in some cases through institutionalization" is hard to understand in the context of this review since there are no recent admissions to the CTC. The comments relate to a child whose parents are considering admission to a facility other than a CTC.

Page 9 - Comments about funding for foster care do not seem relevant to this review.

Page 11 - Comments about "restraint practices" are not easy to follow. The Committee formed a very different impression. The increased staffing in Dartmouth has dramatically decreased concern about restraints and it was not an issue in Sydney.

Page 12 - "Feelings of intimidation" were expressed by a tiny minority of parents. Most indicated that they were comfortable with interactions with CTC administration.

Page 12 - The arm fracture was only recognized two days later. The parent did not articulate sufficient detail about this issue to come to any conclusion.

Page 15 - The contention that "there is little evidence that such planning ..." fails to accept the Department's stated plan to create a transition planning team. In fact, the process is presently underway, albeit not at a pace that some parents may wish.

In the section on decision making, it is important to emphasize that nearly all quotes or use of "some" refer to the same two or three families noted above.

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Page 16 - The Committee did not hear any comments suggesting that "staff don't really care" from any parent who has a child in the CTC at the present time.

Page 17 - The quote "my son" is from a parent whose child is at home and never has been in a CTC.

Page 18 - Prevention of institutionalization in the future is not within the Terms of Reference.

Page 19 - A comprehensive protocol does exist. The Roehrer representatives were assured of this by the Committee on more than one occasion.

Page 20 - The experiences described regarding transition from Pictou, Digby and Dartmouth CTCs would appear at odds with the theme expressed here.

Page 24 - Policy for those currently in the community is beyond the scope of this review.

The Committee disagrees with the suggestions for the Nursing Unit. The well being of these individual children rather than a single philosophical stance must drive all planning for their future placement.

Page 25 - The Committee will not recommend a degree of involvement that should be delegated to the Canadian Association for Community Living or the Family Support Network of Nova Scotia. While we recognize that partnership models do exist in some other provinces (e.g. Newfoundland) where de-institutionalization is in progress, we believe that this should be left as an issue for individual parents or groups of parents to decide, especially given that some parents expressed their unwillingness to have a CACL involved in any transition planning for their children.

The accountability of financial supports is a complex issue, again beyond the scope of this review. There are other stake holders in the accountability including tax payers.

APPENDIX D

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AUG 31 1994

REVIEW OF CHILDREN'S TRAINING CENTRES IN NOVA SCOTIA

A Background Report Prepared by

The Roehar Institute

August, 1994

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INTRODUCTION

This report provides an analysis of information collected by The Roehrer Institute through the course of the Review of Children's Training Centres, and suggests directions for policy and program development. The Institute was contracted by the Department of Community Services to provide technical advice to the Committee.

At the outset of the review, The Roehrer Institute met with the Review Committee to develop a conceptual framework to guide its work in ways that would be consistent with its terms of reference. Those terms stated that the objective of the Review was:

"to assess the current standard and level of operation of all aspects of the Children's Training Centres (CTCs) and to make recommendations for change and all options for care which will result in improved quality of life for residents. Future directions for residents will be evaluated consistent with Government's public statements regarding the provision of services to mentally disabled and handicapped persons."

In advising the Committee, The Roehrer Institute suggested that it was important to clarify a concept of "quality of life" that could be used by the Committee to guide its review and the development of recommendations. It was suggested that quality of life is essentially a normative, value-laden concept and that it should reflect the obligations and commitments made by society and governments. In keeping with this approach it was decided to draw upon the Report of the Minister's Advisory Committee on Services to Children With a Mental Handicap to provide the basic normative elements of a concept of quality of life. This document was the outcome of an extensive community consultation and articulated a set of broad principles, grounded in the commitment of the federal and provincial government to protect and promote human rights for all persons, irregardless of disability. As well, the Nova Scotia government had prepared a response to the Report, indicating support in principle for the recommendations of the Advisory Committee.

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In drawing from the Advisory Committee Report, it was agreed by the Committee that five broad principles should constitute a conception of quality of life to guide the review process. These included:

- equality
- equity
- decision-making in the best interests of individuals
- dignity
- coordination among and within government departments in order to achieve quality of life

The Roeher Institute recommended dropping the fifth element of this concept, as it was not a principle in nature, but rather a condition necessary to realize quality of life as defined by the other four elements.

Together these elements constituted a framework for the Committee's concept of quality of life. The Institute developed a set of broad indicators for each of these four principles. The Review Committee further developed this framework, identified additional indicators, and organized them under 15 issue areas to be examined in the review (e.g. general care, education, health care, etc.)

Concerns and issues raised by parents in focus groups and individual interviews at which The Roeher Institute was present, have been identified in this report. The Roeher Institute representatives, Michael Bach and Melanie Panitch, attended focus groups of parents who have children currently residing at the Dartmouth CTC, and at the CTC in Sydney, and also attended a group presentation and discussion with the Family Support Network of Nova Scotia, constituted by parents who have children with disabilities, some of whom have resided in a Children's Training Centre. As well, they were present at individual interviews with three parents. Two of these families removed their children from the CTC because of concern for the safety of their respective daughters. Both presented statutory declarations to the Committee and to The Roeher Institute outlining their concerns about abuse and injury to their daughters, about the investigations and

responses by The Department of Community Services and the police, and about attitudes of CTC staff and administration. While parents often referred to their particular concerns about their sons and daughters, they also raised more general questions and observations about the CTCs and the community support system.

Undoubtedly, there are perspectives of staff and administration, and of some parents that vary from those presented in this report. However, it was not possible within the parameters of The Roehrer Institute's involvement in the review to carry out a comprehensive survey among staff and parents. Thus, the concerns presented here represent only part of the picture. Moreover, some of the concerns identified refer to one CTC and not the other. Given the separate administration for each CTC, there is much room for variation in procedures, attitudes of staff, and general atmosphere. As well, some of the concerns raised refer to past events. With changes in the administration of CTCs, and staff increases at the Dartmouth CTC, some of these concerns have been addressed.

Nonetheless, the concerns raised do provide valuable information on which to consider the current operations of the CTCs, the extent to which needed changes have now been made, and the role of the CTCs in the deinstitutionalization process. Given that the review has not been designed to "investigate" all of the concerns raised, a statement of these concerns in the report of the Review Committee would provide a basis for a proactive response by the Department and the CTCs. In this way, the Review Committee's report could support the dialogue between the government and the community that began with the Advisory Committee consultations and Report. A response by the Department and the CTCs would enable parents to learn about the extent to which their concerns have already been addressed, and the Department's and the CTCs' plans for addressing their concerns now and in the future.

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It should also be stated that while this report focuses on concerns of parents, many parents spoke appreciatively of the high quality of care their child receives at the CTC, the committed staff, and the hope that their sons and daughters would receive a similar standard of care after leaving the CTC.

Institute representatives did participate in un-structured interviews with the Superintendents of each of the CTCs, and more structured interviews with Ron L'Esperance and Bill McCarron of the Department of Community Services. These interviews were not sufficient to make a detailed assessment of the operations of the CTCs, but did provide additional information to assist in understanding concerns raised by parents.

The first section of this report organizes the concerns of parents under each of the four elements of the concept of quality of life outline above. The four principles provide a vantage point for understanding the nature of concerns raised by parents, and help to shed light on the underlying issues raised by parents. The Roehrer Institute representatives were not able to be involved in all of the interviews and focus groups conducted by the Committee. However, those at which they were in attendance provided a wealth of information upon which this report is based.

The second section of this report provides an analysis of some of the factors underlying parents' concerns presented in this report. Their concerns are rooted in the way the CTCs operate, and in the nature of institutional care for their sons and daughters. As well, their concerns point to *the broader policy environment regulating the provision of support to their sons and daughters.*

The third section identifies directions for policy and program development. The Committee is vested with the responsibility of formulating recommendations for

government. The directions presented here are meant to provide a basis on which the Committee can formulate more specific recommendations.

I. PARENTS' CONCERNS

This section identifies the concerns of parents raised in the interviews and the focus groups in which The Roeher Institute participated, and in the statutory declarations presented to the Committee and The Institute. Concerns are presented under each of the elements of quality of life, which serve as the basis for the Review.

EQUALITY

Equality was defined by the Committee as the principle that everyone should have opportunities to optimize intellectual, emotional, and physical development and well-being, not in a parallel or specialized system, but in the same institutional arrangements, and environments as the general population. Equality is secured by having access to mainstream services, being able to exercise basic civil and citizenship rights, being free from discrimination on the basis of disability, and being protected from abuse and neglect.

A number of concerns were expressed by some parents that the equality of their sons and daughters was not secured by the CTC environment. They believed that the CTC was by nature an institutional facility, and thus would be unable, even if restructured, to secure equality for children with disabilities. Three main concerns were raised by parents with respect to the equality of their sons and daughters who lived, or who had lived in the CTCs.

First, some parents felt that the CTC could not provide a home for their child, and that every child has a right to a home. This being so for these parents, they felt that the CTC

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is not the best place for a child, and that their children cannot reach their full potential as full-time residents in a CTC. These parents felt that children have the same basic needs to be loved and supported, as all other children, but that staff, even of the highest quality, could not play the role of loving and nurturing parents. Some felt that children's rights were denied by having to live in a CTC, their right to belong in the community. As one parent said,

"CTCs can provide care, but they don't provide a home. If I had to choose between my son having a home and having care, I'd have to choose the care, which is the choice I've made. CTC's can't provide both. Of course it would be ideal for him to have both, like in a small option."

Another parent said,

"I sleep in my own room. My son [at the CTC] doesn't. Why not?"

Second, the concern was expressed that CTCs have not promoted the equality of children living there, because they have not been proactive enough in supporting children's involvement in the community. Thus, children are not perceived by the community to be equal with others, and some parents feel there have not been sufficient efforts to include and accommodate them. Parents referred to a number of ways in which they had expected the CTC to promote the involvement of their son or daughter in the community, such as in recreation, integrated education settings, and other community activities. However, for these parents the expectations have not been adequately met. They have not found the CTC forthcoming in efforts to work with community agencies and schools to better include children living at the CTC. Nor have they found the CTC administration willing to allocate sufficient staffing resources on a one-on-one basis so that children could participate in their own particular activities in the community. While some parents found staff and CTC administration supportive of community involvement, others commented that the lack of community involvement is a significant limitation of life at a CTC.

Third, the concern was expressed that children have suffered a violation of their rights, not only by having to live at the CTC, but by virtue of the procedures and operations of the CTC. Parents pointed to a number of ways in which they believed rights had been violated including confining children to a "time-out" room, according to a parent, for "hours at a time"; or restraining children by tying them to toilet seats for periods of 15 minutes; not enabling children to exercise their right to education, because of limited educational activities for those confined to the CTC during the day.

Parents' concerns regarding the handling of allegations of abuse or injury by CTC staff or other residents also indicated a concern that children's civil rights have not been adequately protected. One parent indicated that police would not proceed with a fuller investigation of allegations of sexual abuse at the CTC because her daughter would not be able to testify, or provide information about the allegation. Even though there was physical and behavioural evidence that her daughter may have been sexually abused at the CTC, the investigation was closed much before the parent believed the case should have been dropped. Some parents attributed the lack of protection of the civil rights of children in the CTCs to police attitudes towards people with disabilities, attitudes which one parent believed indicated that they are "woefully uneducated about disability."

EQUITY

Equity, as defined by the Review Committee, refers to the access to needed supports that is necessary in order to obtain equality in society. Thus, individuals need supports that are responsive; comprehensive; portable across programs, life stages, and geography, that are flexible, accessible and available; sensitive and responsive to cultural, racial, and linguistic heritage; and that are adequately funded.

Based on the concerns expressed by parents, equity has not been achieved for the individuals who reside at CTCs. This is due in large part to the lack of equitable access

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to needed community supports that leads parents to place their children in institutional facilities like the CTCs in the first place. Many parents felt that the fact they had to place their children in an institutional facility was evidence of a profound inequity in society. Once their children are residing at the CTCs, some parents have also found that their children lack equitable access to the supports they felt the CTCs should be able to provide.

The concerns of parents about equity revolve then around two main issues: the lack of community supports, and the inadequacy of supports provided by the CTC.

Some parents indicated that the current lack of community supports for children and families means that non-means-tested institutional care is still the only option for some families. One parent said he felt "held hostage" because unstable, insecure, and inadequate financial support and services force parents to place their son or daughter in an institutional facility where there is at least some sense of security. A couple of parents indicated they had been so desperate for support they took their children to the CTC, without prior arrangement, and left them with the staff; full of feelings of guilt and worry but unable to do anything else because they had insufficient supports. And, the perception of some, is that if you do not give your child up to an institution you do not get services needed. Community supports continue to be very unstable, and parents generally felt they will only be able to have children at home if stable, secure and continuous supports are in place. One parent said it felt like having to "jump through the hoops" to get what is needed for education, community involvement, and for family support. A number of parents indicated that lack of respite services, and funding to purchase respite is leading to a crisis in many families, that is still being resolved in some cases through institutionalization.

For those whose children who remain in the community, parents find a number of

inequities in provision of support. Government does provide more supports to foster families, than to natural families. If a natural family gives up their child to a foster family, the foster family can get financial supports for which the natural family remains ineligible. Some parents indicated other inequities, with some parents getting more supports than others, even though the needs of their children are the same. Parents who have removed their children from the CTC after allegations of abuse or injury have found they immediately began to access much more extensive community supports than before they had had to place their child in the CTC, even though their needs had not changed. Individuals who are living in CTCs are getting a much more financially intensive level of support than those living in the community, even though the needs may be similar.

The lack of community supports has led families to place children in the CTCs. It has also led to a growing mistrust in government. According to some parents, recent cutbacks to adult disability pensions does not breed trust in the government's willingness to ensure support to people with disabilities, or in their claims that the children in the CTC will receive adequate support once they move to the community. Parents do not know where their sons and daughters will move after the CTCs close. While many look to the "small options" homes as the best option, many are concerned that the government will not provide the needed funding. One parent indicated that her biggest fear is that if the CTC closes, and her daughter goes to a small option, that the government will cutback, and her daughter will have to leave there. Another parent indicated that it is difficult to have confidence in an outside option. At least the CTC provided ongoing care. Another parent indicated that a small option was promised to her daughter a year and a half ago by one of the most senior officials in the Department, only to be told later that the item had been dropped from the budget because of fiscal constraint. One parent said, "there has been a "bureaucratic dangling of a carrot - we've been told so many times that things are going to change, and they never do." A mother and father who removed her daughter from the CTC after she had received second degree burns, that

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they felt had not been sufficiently explained, waited 18 months for long-term planning for community supports to begin. Yet according to the parents, the government has not yet made clear the nature of long term entitlement to the family, leaving the parents with uncertainty about the future of supports for their daughter.

Once parents have placed their son or daughter in the CTC, some have found that equitable provision of supports continues to be an elusive goal. Some parents have found that even though they are assured of individualized programming, they have not found this to be the case. There is a perception by some parents that children have to get up at the same time, have meals at the same time, go to bed at the same time, even if that is early on a Friday evening. At one time, parents found children lined up in the hallways watching television. Although, this practice does not appear to continue, some parents indicated that in the CTCs or any institutional facility it is difficult, if not impossible, to provide the kind of individualized activities they want for their sons and daughters.

Parents have seen the consequences of inadequate support. For instance, one child was left sitting in the sun while staff attended another child, resulting in a serious sunburn to the child left unattended. In another example, the lunch that accompanied one child to school was lumpy and indigestible and posed a respiratory risk. Despite constant communication from the school and parent it took four months for this to be resolved by the CTC who finally purchased a blender for this purpose. As well, although there are some long-term staff, some parents believed there to be a lack of consistency in staff and high turnover rates, which they felt makes it difficult for individuals to develop trust in the people they need to depend on for so many personal needs.

Access to what many parents saw as already limited opportunities in the CTC was also restricted. One parent indicated she had never seen a child on the trampoline, believing

it is a "showpiece" only. Some felt the play equipment outside Dartmouth CTC was "never used", or rarely so. While some individuals are able to access summer programs like summer camps, one parent believed this to be the case for only some individuals each year, others not enjoying access to these opportunities until other years.

Lack of adequate staffing at the Dartmouth CTC was identified by the Department as a serious issue, and in the past year significant increases in staffing resources have been accomplished. The increase in staffing did address certain concerns of parents. For example, the impact of the increase in staff was described by parents in terms of: individuals were no longer "wandering the halls"; "for the first time all those rooms were being used"; "the accident rate went down"; and "there were not nearly the amount of ripped clothes" because of individuals being "so bored and frustrated, they would eat them".

However, increase in staffing alone does not fully address the issues raised by parents of limited access to opportunities in the CTC and the community, regimentation of children's days, lack of responsiveness to individual needs, and restraint practices. While staff have increased at Dartmouth CTC, to some parents it is not clear that this has made staff involvement with individuals any more meaningful.

DECISION MAKING IN A PERSON'S BEST INTERESTS

Decision making in a person's best interest was defined by the Committee as having an individual plan in place that reflected a personal vision, aspirations and support requirements, and that took into account factors such as where a person wanted to live, who he or she wanted to live with, what supports were needed, etc. Decision making should be carried out in ways that keeps the individual at the centre of planning; provides opportunities for input from individuals and their advocates, family members and service providers.

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expressed by parents indicate that this approach to decision making has by and large been achieved. A wide range of concerns were expressed by parents about the lack of communication between parents and the CTC administration, feelings of intimidation resulting from interactions with staff and administration, lack of involvement in planning for their sons and daughters, lack of independent advocacy to ensure that children's interests were held first and foremost when parents were not available or able to advocate, and lack of mechanisms for long-term planning for community life.

The issues and concerns raised by a number of parents suggests that there is the absence of trust and open communication between some parents and staff and administration at the CTCs. Without these conditions decision making in the best interests of children is highly unlikely.

For example, a few parents indicated they had been told verbally and by letter in some cases not to talk to front-line staff about their concerns. Some parents feel intimidated by staff who, they feel, assume "what's best" for their son or daughter. Some parents were concerned that if they spoke up about their concerns, there might be consequences for their son or daughter. One parent said it was "like walking on eggshells" everytime she approached the Superintendent of the CTC. She felt like a child who was going to be "chastised" by the Superintendent for something she had done. One parent had staff express concerns to her about lack of staff, but was told that if staff approached administration with the concern, that staff could be fired. Another parent described the constant focus by CTC administration on her (in)ability to be a mother, as "parental abuse". Another parent was concerned that there was little interaction with staff when the parents returned to the CTC with daughter after having her home for the weekend, no queries from staff about "how the weekend was," etc. The lack of communication between parents and staff was epitomized for one parent by the experience of her daughter falling out of a chair at the CTC and breaking her arm. Yet

the parent only learned about the incident two days later.

Without open and trusting communication, parents believed that the decision-making by staff about their son or daughter was inevitably compromised. For one parent, trust and communication were absolutely undermined when the Superintendent of one CTC solicited comments from staff about their concerns about the parent. The comments were then read back to the parent at a meeting with the Superintendent, called to review the parent's allegations that the CTC had refused to take responsibility for second degree burns to her daughter's neck. The CTC administration's response to concerns and allegations of abuse by parents was considered by them to be defensive, unsupportive, and disrespectful.

Some parents did indicate they had full trust in the facility to respond to parents concerns or allegations. They indicated they have no reason not to trust. "If you didn't have the trust you couldn't leave your child here." It appears that it is precisely when some parents lost their trust in the CTC that they moved their child back to the community.

Decision making in an individual's best interests also requires a planning process in which the interests and wishes of the individual, and the hopes of the parent for their son or daughter, can be fully explored. Yet, on the basis of concerns raised by parents, such a process appears to be lacking. A number of comments by parents point to limitations in the current individual planning process.

Parent's requests for particular programs for their son or daughter have not been followed through it appears in some cases. Some parents indicated that they did not feel included in decision making, including the Individual Program Planning (IPP) process. They suggested that staff see the ongoing individual planning as a staff exercise, and not as one to be driven by the parent's wishes for their son or daughter, or by the individual's

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wishes him- or herself. As one parent indicated, "There was no one taking any responsibility to find out who my child was, there was no one who was accountable." Some parents indicated they were not invited to IPP meetings, and one parent was told by staff that the parents' input to IPPs was confined to the Voluntary Care Agreement signed between the parent and the CTC. Yet parents indicated they wanted ongoing input into every aspect of their child's life, and wanted the CTC to solicit their input. Some parents indicated this rarely happened.

Nor have some parents been satisfied with the plans that have been developed by staff. One parent indicated that the plans tend to be "medically oriented". One parent looked at the plan developed for their son or daughter and asked, "Where is my child in all of this?" The educational plan that was put in place by the CTC for one individual who remained at the CTC during the day was felt by one parent to be entirely inadequate, in that her daughter was only seen for two 45 minute periods a day by the teacher at the CTC.

There was also a concern raised by some parents that no IPP was in place for their children at all. One parent indicated that the essential components of any IPP for her daughter would have included physiotherapy and the jacuzzi, neither of which her daughter had experienced in two years.

Another concern raised about decision making was that parents were asked to delegate their consent to medical treatment, immunization, surgical operation, dental treatment, administration of anaesthetics or any other form of health care. It was felt by one parent that this was an abdication of the rights and responsibilities of parents, that it was unwarranted, and that it gave powers to the CTC to make decisions far beyond what was in the children's best interests. It was felt that parents should not only be notified of such decisions, but that their consent should be sought for each and every medical or health

care intervention.

Decision making in the best interests of children can also be supported by a system of advocacy. Advocacy ensures that individuals' wishes remain at the centre of the decision-making process. A system of advocacy or "key counsellor" roles has been put in place that allows staff members to act as advocates within the CTC for a designated individual. Some parents expressed a concern that this represented a conflict of interest for staff members because their advocacy would not be independent; that is, they would be reluctant to "buck the system" for the individuals living there, because the "system" was their employer. Some parents indicated that evidence that this form of advocacy had not been effective could be found in the fact that the CTC had not advocated effectively to assist children in gaining access to inclusive education. Some parents suggested that referring to the current arrangement as "advocacy" is a "misnomer".

Some parents also expressed a concern that parents advocating as a group was essential to the well-being of their children, and to a decision-making process that operated in their best interests. Some were concerned that parent advocacy will dissipate with the closure of the CTCs because parents will not as easily be able to meet each other as a large group.

Given that the CTCs are closing, some parents also expressed a concern that an adequate decision-making process that will lead to a quality of life in the community is not yet in place. They felt that planning for the transition to the community should be underway now, given the amount of time it takes to establish viable community supports for individuals, and to prepare the individual, the family, and the community for the return to the community. Yet there is little evidence that such planning is underway in any systematic manner.

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Finally, a decision-making process in the best interests of children requires an investigation process for complaints and concerns that is independent, and maintains respect for all parties involved. Otherwise it is difficult to ensure that children will remain at the centre of the process, and that all relevant and necessary information and concern will be expressed. Yet one parent felt that *she and her daughter had neither been adequately respected or supported by the process of investigating and responding to her concern that her daughter may have been sexually abused at the CTC.* Some parents also expressed concern that investigations of such matters of abuse, injury, or neglect should be more independent than they currently are. The Departmental involvement in investigations, and Departmental reports on the conclusions of investigations, are suspect by some parents because they feel there is a potential for conflict of interest by the Department.

DIGNITY

Dignity was not defined at the outset by the Review Committee. The Institute did provide a set of indicators which characterized dignity as the state of: being respected by others; having the need for privacy respected, being free from abuse and neglect; having personal possessions reflecting what is important to a person; having access to services that are non-labelling, non-stigmatizing, and respectful; having self-confidence and self-esteem enhanced through relationships with services providers; having individual plans which emphasize personal strengths, capacities, and potential.

Many parents expressed concerns that the basic dignity of their children was not secured or promoted by the operation of the CTCs. They had observed that in some instances children have been left unattended, strapped to chairs or toilets, and had heard staff referring to the CTC as a "zoo". Because of what appears to them as high turnover, some parents are concerned that certain staff don't really care about their son or daughter. Parents were also concerned that individuals lack privacy in the rooms they

sleep in, where they have to sleep with four to six other individuals. At the Dartmouth CTC many parents indicated they saw their sons and daughters in clothing that was not their own and in some cases never saw articles of clothes (or toys) that they had bought especially for birthdays or Christmas: "they would disappear". In at least one instance these were even labelled by the parent, in another this included sneakers critical for the child's mobility. Yet according to one parent, "staff couldn't grasp how important it is not to highlight our daughter's disability by wearing too large or soiled clothing, that she has some self-esteem".

Some parents expressed concern that the consequences of institutionalization, and the nature of institutional care at the CTCs, undermined the dignity of their children. One parent observed that her son developed self-abusive behaviours after entering the CTC because, she believes, her son was left without support, involvement with others, or activities. Other parents have watched their child regress in their physical and intellectual functioning after they entered the CTC. When children return to the community, some parents have seen them begin to flourish almost immediately. One parent indicated that her daughter would enter the CTC for respite but for no longer than a week because the level of care was so low "there was no one to talk to her"; consequently she would hardly talk when she got home. Another parent would arrive to find daughter often sitting by the radiator alone. After two weeks in respite care at the CTC one individual learned to chew his hand because, the parent felt, the activities for him were too limited. As his mother described it "the TV was up on the shelf and he never thought to look up" the way the other residents who were lined up did.

That the dignity of their sons and daughters is paramount to parents is perhaps best summed up by one mother, who stated.

"My son is severely challenged, he is never going to fly on his own, but I want him to have dignity and to be treated with respect. He is a human being and I want him to be appreciated for the person he is... When he's looking into my eyes

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I know he loves me, he has a soul. He's a person, he has a right to be here like anyone else."

Yet for many parents this kind of respect and treatment was too often undermined by the CTC, and too rarely accorded their sons and daughters.

II. FACTORS UNDERLYING PARENTS' CONCERNS

In their identification of this wide ranging set of concerns, parents, and others who were interviewed, pointed to seven key factors that are at the root of inequality, inequities, lack of decision-making in children's best interests, and the undermining of their dignity.

First, as already indicated, the lack of community supports for parents led to their decision to place their son or daughter in a CTC. It is apparent that this lack of secure and adequate community supports persists as a major problem for parents and children with disabilities. One parent who appeared before the Committee indicated that she had decided to place her child in an institutional facility in the near future because she cannot obtain the supports. Such examples point to the fact that while a government decision has been made to close the CTCs, this in itself will not prevent institutionalization in the future. Unless an adequate community support system is put in place, parents may well experience the "revolving door", moving their son or daughter from one institutional facility to another, whether a nursing home or adult residential facility.

Second, comments from a number of parents indicated that the CTC, by nature is unable to secure equality, equity, decision-making in a child's best interest, or dignity for their sons and daughters. Reform of the institutional facilities or operations, from the perspective of some parents, is not a viable option as it will not be able to provide a quality of life for their son or daughter consistent with these principles.

Third, there is a lack of an accountable decision-making process with mechanisms to

manage individual planning and decision making in ways that keep individuals at the centre, and ensure status for parents. Such processes and mechanisms are necessary conditions to secure the quality of life of children with disabilities and their families. Yet they have not been put in place, in a systematic way, for the children at the CTCs and their parents.

Fourth, there is a lack of a transition planning process that will secure a high quality of life for children upon their move from the CTCs. Parents are not convinced that there is a plan in place to ensure a smooth transition, or that options are available, or will be available to adequately respond to the individual needs of their sons and daughters.

Fifth, the CTCs are not doing all they could be doing to assist parents and children in preparing for the move to the community. A staff orientation to community living, human rights, and community development is lacking, and thus CTC are not as proactive as they might be in creating opportunities for community inclusion.

Sixth, a comprehensive protocol for responding to complaints of abuse, injury, or neglect does not appear to be in place for the CTCs, and it is not clear whether a systematic protocol is in place for community services. Consequently, parents have not understood what the complaints and investigation procedure is, nor have staff, nor have parents been clear about the kinds of supports they or their children should expect.

Seventh, it is apparent that a policy framework is lacking to secure provision of supports to individuals with disabilities and their families that meet the tests of equality and equity defined above. Policy and programs are fragmented leaving families without adequate supports, and leading to immense inequities in the system. The government has promised a policy on deinstitutionalization which may address current gaps, but this policy was not available at the time the Committee was undertaking its review. Thus, it is not possible

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to determine whether the policy will meet the concerns of parents, the principles outlined by the Advisory Committee, or the concept of quality of life presented above.

III. DIRECTIONS FOR POLICY AND PROGRAM DEVELOPMENT

Based on parents' concerns, and factors underlying these concerns, as well as parents' own recommendations about what is needed, a number of directions for policy and program development are identified below:

1. Development of an Individual Planning and Decision-Making Process
2. Development of a Plan for Transition Planning and Community Development
3. Establishing a Complaints and Concerns Policy
4. Development of Protocol for Prevention and Response to Abuse
5. Development of CTC Staff
6. Preventing the Revolving Door
7. Making Advocacy Support Available
8. Development of Family Support
9. Need for a Partnership Arrangement
10. Development of a Policy Framework for Security, Responsiveness and Flexibility

1. Development of an Individual Planning and Decision-Making Process

In order to address parents' concerns about the lack of individual planning and the current decision-making process in the CTCs, the individual planning process should be redesigned. In accordance with expectations and experiences of the transition planning process, parents should be much more actively involved. The plans should anticipate children's move to the community, should emphasize the development of a vision for the child in the community, should respect parents choices but provide as much information

as possible about options. The plans should incorporate some attention to functional development, but should be driven much more by a vision of the child's life in the community and what can be done now at the CTC to help prepare for the realization of that vision.

The blanket waiver of consent parents are now asked to sign should be re-considered. It presents an enormous abdication of parental responsibility and right to provide consent for treatments to their child. Hopefully, such consent arrangements will not be established in the community for parents. Thus their role in health care decision-making should be changed now rather than later so they can begin to gain an understanding of the health care decisions that are made on an ongoing basis about their son or daughter.

2. Development of a Plan for Transition and Community Development

A plan needs to be in place, designed by the Partners (see #10 below) to the process, that provides for adequate planning support to parents. As plans are developed for individuals' transition to the community, many kinds of needed supports will be identified such as housing, training and employment opportunities, provision of personal supports. *Some capacity is needed to enable the development of such resources.* The transition plan should include attention to mechanisms for providing families with information about available options, and should enable families to visit various options in the community prior to their making decisions about their sons and daughters.

The transition plan should also identify means by which planning support will be made available to parents. Some parents have indicated they wish to choose planning support themselves, and that they should have planning support autonomous from government and the CTCs.

Parents also indicated they wish the planning process to be designed in a way that will

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ensure they have control over decisions including:

- living arrangement
- safety
- hiring of the staff
- the individual programs

The Department of community services has supported a comprehensive transition planning process in the case of one parent who withdrew her daughter from the CTC after allegations of abuse. The parent had input into selection of planning team, there was a lot of leeway to try different options, her daughter was always at the centre of planning, and the committee had flexibility. The Department was represented on the planning committee so that someone was present who had the authority to make funding decisions. Such positive experiences should be built upon as a more systematic transition planning process is established.

In order to make the transition as successful as possible, the CTCs need to more actively assist individuals to become involved now in community life in a much more extensive way. This may entail a role for the CTCs or some other agent in assisting community services to become more open, inclusive and accommodating of individuals.

3. Establishing a Complaints and Concerns Policy

A policy for CTCs on complaints and concerns of parents should be established, laying out the avenues for parents to express concerns to staff and CTC administration. The policy should be flexible, emphasizing the right of parents to raise concerns with any staff member, as it is staff who are directly involved with their children. The administration should make clear to parents that they welcome expressions of concern by parents.

In order to address the problem of intimidation some parents feel, other avenues should

be considered as well. One option is to establish a complaints committee, constituted by parents. As an autonomous committee, parents could approach the committee to express concerns and seek support of the committee in approaching the administration.

4. Development of Protocol for Prevention and Response to Abuse

A protocol is needed, consistent with child and adult protection legislation. The protocol should clearly identify the process for making complaints of suspected abuse, violation of rights, of injury, or neglect. The protocol should identify the kinds of responses that will be available, and should guide the linkage with other affected agencies including police, other service agencies, and the Department as a whole. As well, a protocol is needed that secures the integrity of investigations into complaints, and is structured in a way that responds to parents' concerns about conflicts of interest in investigations and lack of independent investigation.

5. Development of CTC Staff

A investment in staff training and development is needed. An intensive effort is required to shift attitudes of some staff to both children and parents, with an emphasis on the rights of children with disabilities and their parents, prevention of and response to abuse, and the importance of community inclusion. As a reformed individual planning process is put in place, staff should be trained in the new process, in order to understand the underlying values and assumptions, and the respective roles of the parties involved.

6. Preventing the Revolving Door

The commitment by government to move from institutional care to community support, for all children with a disability should be re-affirmed. This commitment should be made cognizant of the continuing pressures on parents to institutionalize their child given the lack of community supports. A policy for deinstitutionalization of the CTCs must, therefore, address at the same time the development of community supports and access to

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services, not only for children and adults now living in the CTCs, but for those now living in the community who are at risk of institutionalization in nursing homes or other residential facilities.

Special consideration will need to be given to the children now in the nursing unit at the Sydney CTC. While these children have significant needs, are considered "medically fragile", and are reliant to varying degrees on technological support, these factors do not in themselves suggest that institutionalization is the only option. Community living should be affirmed as the goal for all children, and appropriate community options established for these children. Other children with similar needs are living with support in the community in Nova Scotia and in other parts of Canada. Information about these options should be provided to parents of children on the nursing unit, as soon as possible and transition planning should begin immediately.

7. Making Advocacy Support Available

Given ongoing concerns of parents about the conditions at the CTCs and the treatment of children living there, an independent system of advocacy should be instituted. Advocates should be made available, at the discretion of parents, who are independent of the department and the CTC. Where parents are not able to play the advocacy role, independent advocates should be found for this purpose. Resources could be provided to the Association for Community Living, the Family Support Network, or a separate community board to provide such services. Advocates should be empowered, with the consent of parents, to enter the facility at any time and have access to the files of the individual for whom they are advocating.

8. Development of Family Support

Parents indicated the importance of developing parent-to-parent mutual support. Parents can offer each other emotional support, information about what to expect, and support in

parents' dealings and negotiations with the CTC or the Department. Research on deinstitutionalization suggests that mutual support is an important factor in effective transitions to the community. Resources, independent of the CTC, should be made available so that parent groups can be fostered. The Association for Community Living and/or the Family Support Network of Nova Scotia should be involved in developing family support.

9. Need for a Partnership Arrangement

Some parents indicated the need for a partnership arrangement to manage the closure of the CTCs and the development of community supports. It was recommended that partners should include government, parents, and the Association for Community Living. Such a partnership would reflect those now being developed to manage deinstitutionalization initiatives in other parts of Canada.

10. Development of a Policy Framework for Security, Responsiveness and Flexibility

Policy options now being developed should be examined for their responsiveness to the concerns raised by parents. A policy framework is needed that provides a secure entitlement to required services and supports. The framework should enable allocation of funding to parents or individuals so that they have flexibility in options and are able to transition into new arrangements as the need arises. Funding and planning arrangements established should maximize the decision-making role of parents. Arrangements should ensure that adequate planning resources are in place, that are accountable to parents, and that provide needed information and support.

APPENDIX E

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