



RESPITE CARE

DEFINITION

"The temporary care of a disabled individual for the purpose of providing relief to the primary caregiver." (Cohen and Warren in Deiner and Whitehead)

"Respite care is a temporary service provided to caregivers who have disabled, elderly or chronically ill persons living in their homes who require specialized care. Home support and holiday relief are provided either through the use of respite workers, relieving the caregivers in the home or through placement of the individual in an alternate place of care." (Inter - agency Committee on people with disabilities, NWT 1991)

Respite care is included as or part of home support services described in the Department of Social Service descriptions. While program description & levels of service are not specified it is none the less anticipated that respite care is part & parcel of a home support program.

The need for such a program has become more pronounced as more disabled people are able to remain with their families in their own communities. As never before disabled people are mainstreamed and cared for by members of their own families. The conscious effort to provide for the special needs of disabled persons in their own community means that resource are often stretched. Particularly so in the case of parents of disabled children. When these children attend school they have the services of an assistant, parents on the other hand often have so assistance to augment the care they have to provide.

Despite the move to have disabled persons remain with their families the government has done little to enhance the life of disabled residents or to assist the parents & care givers of disabled people.

The majority of services are directed to the client (ie. physio therapy, special education) with little attention being directed to parents or caregivers. This lack of support leads to stress & burnout and ultimately to higher costs.

In the NWT there are over 20 communities which have homemaker / home support program. These services have primarily been directed to the sick & elderly. It would be possible & feasible for a respite care service to be provided under this community program. The level of service would have to conform to the available of staff, & the overall demands of the program.

Types of care provided could include:

- * 1-4 hours during the day or evening so that primary caregiver can have an evening out, go on personal errands or socialize.
- * accompany the person with a disability to an event outside the home.
- * "weekend" relief - 24 or 48 hours break
- * holiday relief- one to four weeks while the primary caregiver goes on vacation or goes out on the land.
- * crisis relief - when situations are at a crisis stage and unhealthy.
- * Short / long term stays in group homes, senior facilities, hospitals, shelters.
- * camps for people with disabilities.
- * homemaker and homecare services provided to the caregivers.
- * daycare, after-school programs where a special needs assistant is provided.

For respite care to be provided a policy decision is required to address such things as the level or types of care provided, fees & criteria for services, and of course training for the care providers.

The type of service, its cost & criteria vary across Canada, it is however well accepted that respite care is part & parcel of a program of services directed toward disabled persons and their families.

SERVICES OUTSIDE OF THE NWT

YUKON

Home Care

- average support 4 hrs a week, maximum 35.5 hr/wk per client
- up to 12 hrs per week respite for primary caregiver

Homemakers, DIAND

- homemakers are hired through the band to assist those in need
- at present no policy for respite

Teegatha Oh'Zheh

- service society that provides 24 hour care to two adults with mental disabilities in a home rented in their name.
- funded through Vocational Rehabilitation Services.
- provided respite to one other adult at a time

Nursing Options

- professional nursing service
- \$30.50 per hour

RESPIRE SERVICES, NEWFOUNDLAND

- short term - qualified worker goes into the home or family member goes out. Provided regularly or intermittently
- residential - provided by families in licensed private homes over an extended period of time. From one night to one month.

FAMILY SUPPORT SERVICES, MANITOBA

- provided by Health and Family Services
- only available to natural or adoptive families, not child in care
- provides up to \$3000 per year in services
- Additional Care and Support provides up to \$12,000 in service for special cases
- families do not receive cash for services but are reimbursed for costs ie respite care, training.

SASKATCHEWAN

- Community Resource Homes - short term residential care for persons with mental or physical disabilities during holidays, time of crisis, or for relief. Homes in 6 communities.
- Outreach programs provide services that do not have access to

Holiday relief - for up to 3 weeks.

Respite relief - for a day or a weekend to reduce ongoing stress on family.

Crisis relief - when serious problems develop or coping abilities diminish.

- services available for up to 60 days per year, family contributes \$7 per day.
- Social Services finances the program and community groups administer the programs.

HOST FAMILY PROGRAM, ALBERTA

- temporary, planned respite for parents with children with physical or mental disabilities.
- host families are screened and take 6 training sessions, there is a probationary term and ongoing monitoring.
- host families are expected to offer minimum of 24 days and maximum of 62 days. Hosts paid \$40 per day.
- parents pay \$5 per day.

COMMUNITY OPTIONS FOR CHILDREN AND FAMILIES, VICTORIA, BC

- non-profit society

Provides:

Family care - outside the child's home but family environment

In home care - in child's home by approved caregiver

Out of home care - caregivers who will accompany the child to community events.

Fees on sliding scale \$6.28 - \$10.66 (1987) for parents and charge back to government for \$60 per day and families allocated 28 respite days per year.

PROPOSAL FOR RESPITE CARE POLICY

The NWT Council for Disabled Persons is calling on the Government of the NWT to create and implement a policy on respite care for people with disabilities in the NWT.

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Background

Historically, people with disabilities were often sent to institutions in the south. As we recognize the right of people with disabilities to be a part of community life, to enjoy an integrated lifestyle, we must provide the supports to families so that people are in healthy home environments.

When children with disabilities are in school, they have a special needs assistant. When the child is at home, there is no help for the parents. This lack of support leads to stress and burn out. When people with disabilities are out of the school system there is rarely any activities for them in the community. Jobs are scarce. This means they are in the home 24 hours a day and needing care. When families cannot cope they often end up putting their family member in group homes, hospitals or foster care. This is very expensive and is not fair to the person with a disability.

Types of Respite Care

- * 1-4 hours during the day or evening so that primary caregiver can have an evening out, go on personal errands or socialize.
- * "weekend" relief - 24 or 48 hours break
- * holiday relief- one to four weeks while the primary caregiver goes on vacation or goes out on the land.
- * short term stays in group homes, senior facilities, hospitals
- * daycare, after-school programs where a special needs assistant is provided.

Other Jurisdictions

In the Yukon, the homecare program provides up to 12 hours per week for respite care.

In Alberta, host families offer a minimum of 24 days per year and a maximum of 62 days to care for a person with a disability. Host families are paid a daily rate and the families make a \$5 per day payment toward the service.

In British Columbia care can be provided outside the home but in a family environment or in the home with an approved caregiver. Fees are based on a sliding scale for the family and approximately 85% of the fee to caregiver is paid by the government. Families are allocated 28 respite days per year.

Solutions

A community based program must be developed which responds to needs of the individuals and uses the existing resources within the community.

A system should be devised that talks to people with disabilities and their families to see what their respite care needs are. Then families in the community should be asked to provide this care.

For example, parents of child with autism would like have a weekend to go out on the land. Another family in the community has offered to be a respite care family. The respite care family is trained by the parents and other community members about what the child needs and how he communicates. The child with a disability then stays with the respite family while his parents are away. The family that looks after the child for the weekend, is paid a daily fee by the government.

Another community based solution is the homecare/homemaker programs. In the NWT there are over 20 communities which have homemaker/ home support programs. These services have primarily been directed to the sick & elderly. We should build on this existing service to provide respite to people who are caring for people with disabilities.

A respite care policy must address the types of care to be provided, fees & criteria for services, and of course training for the respite care providers.

If people cannot care for their family members then Social Services makes money available to put people in group homes, institutions and foster care. Let's use some of the money that you are saving by not having to provide this care, to assist the people that are providing safe, integrated family homes.