



# Independent Living Resource Centre

## ***ILRC Focus Groups Home Support-2008***

***A report of the findings and  
recommendations of a  
consumer focus group on the  
challenges facing people with  
disabilities.***

***April 9, 2008***





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## ***ILRC Focus Groups Home Support-2008***

The **Independent Living Resource Centre** or ILRC is a resource centre designed by and for people with disabilities.

We are...

- Located in St. John's, Newfoundland & Labrador, Canada
- A not-for-profit community based organization
- Managed by a consumer controlled volunteer board of directors
- Open to people who have any type(s) of disability
- A member of Independent Living Canada (ILC) (previously the Canadian Association of Independent Living Centres, CAILC.)

As well, we offer a wide range of disability related information, services and resources. Our goal is to support people in making informed decisions about their lives.

Independent Living is about:

- Having choices
- Making informed decisions
- Finding solutions that work for you
- Choosing where and how you want to live
- Taking risks
- Taking responsibility
- Managing your resources
- Controlling your own supports
- Learning from each other

A consumer is a person with a disability. Instead of being "patients" or "clients" we see ourselves as active and informed consumers of products, programs and services.

Focus groups, initiated by the ILRC, took place on February 18<sup>th</sup> & 25<sup>th</sup>, 2008 with 26 people in attendance on February 18<sup>th</sup> and 25 people in attendance on February 25<sup>th</sup>. The following is a summary of these meetings as reported by the consumers who attended the focus group sessions. Following completion of a draft document, we met again on April 9<sup>th</sup> to review the contents of the report and make final revisions.



As we understand, there are a number of terms that comprise Home Supportive Services. They are:

- 'Home care' referring to the medical model
- Home support referring to the Independent Living model
- Long term care
- Care giving
- Respite care
- Continuing care
- Palliative care

There are historically negative connotations connected with the words 'care giving' and 'care givers'.

Rather than using terms referencing 'care', we prefer to use the term 'support' because it places the individual with a disability in a more active role.

Other term suggests a person with the disability is 'needy' and in passive need of care. The word 'support' places the person with the disability as an active decision-maker involved in whatever support services are necessary that would empower her/him to take an active role in society.



## ***Findings***

Problems identified by people using the services of home support:

1. 'Home support' required by people with disabilities is perceived by consumers as different from, for example, 'home care' required by people discharged from hospital. This is not to say people with disabilities would not require personal care but rather they distinguish such care as only one piece in the larger concept of home support; which denotes more broad and diverse need.
2. Providing home support is multifaceted and complex.

- Many people take simple tasks, such as housekeeping, for granted. But some consumers find such tasks difficult or even impossible to complete and need support in order to keep their living environment comfortable, safe and secure.
  - Home support workers may misunderstand an untidy home as a sign of “laziness” rather than seeing the issue as a need for increased home support service.
  - Sometimes home support workers report *client* untidiness to their agency. This changes the relationship between consumers and workers and makes the consumer feel shame and judged. It often places the worker in an authoritative role rather than one of employee. Problems such as these are often because of insufficient support and being too overwhelmed to know how to fix the problem.
  - There are also individuals who wish to do more with assistance. One consumer states, “Too much is done for me, I would like the home support worker to involve me more.”
3. Consumers do not want paid strangers entering their personal space. Requests for home support occur only when it is essential.
- One person asked, “Would you want a stranger coming into your home?”
4. Needs Intake Assessments limit the type and duration of Home Supportive Service a person with disabilities can access with the assistance of government funding. The person who is ‘eligible’ for government funded home support is limited by traditional needs assessment and this service often considers physical need only.
- Consumers state such assessments do not ‘fit’ issues faced by all people with disabilities.
  - A study performed by the Canadian Mental Health Association reported people with mental health issues all benefited with varying amounts of home support.
  - Consumers of mental health services state they feel excluded by rigid assessment criteria. One consumer explained, “My needs are as invisible as my disability.”
  - Sometimes people with disabilities are unable to adequately articulate their need during assessments.
5. Serious gaps exist within the system.
- Consumers of mental health services report going from service to service in an effort to find the support needed in a time of crisis. This support leads them through superficial system stopgaps that provide band-aid treatments rather than tackle underlying issues.

- Consumers report that the Crisis Line advises you to seek help in the hospital; however, hospitals usually prioritize patients by physical need.
  - More frequent users of the Crisis Line state they gained the label of *repeater*. Labels of this type can predispose a consumer to police intervention. This process or the perception of such negative reinforcement makes consumers less likely to seek such help.
  - Feelings of isolation can stimulate or contribute to a crisis.
  - Consumers ask, “Do things really need to progress to the level of crisis before support is provided?”
6. “One size fits all” – is **not** a philosophy that can be applied to Home Supportive Services!
- Training in basic principles of Independent Living, right to respect, right to choose, right to take a risk, and taking responsibility, and basic First Aid is all of the training some people with disabilities want from a home support worker.
  - Others feel more comprehensive knowledge is required for their home support. With such a wide range of varying need it is simply not possible to ‘rubber stamp’ training required for Home Support Services.
  - Training must involve community values and cannot only focus on medical models of providing care.
  - Feelings of isolation and frustration are increased when a different worker appears each day. There is no continuity and this requires extra energy, as each day becomes a home support worker training session rather than a consumer support session.
  - For some people with disabilities access to home support would provide that little extra emotional support that would permit the individual to continue to live in her/his own home.
  - Availability of support services in rural areas decreases the sense that one has to move to urban areas to receive adequate support.
  - Consumers agree, “Government assessment needs to be more flexible in centres where housing projects are not available; especially in rural areas of the island and Labrador.”
7. Consumers frequently report they do not know how to properly manage Home Supportive Services. They are not always aware of their rights, the rights of workers, or how to cope when conflicts arise.
- “How do I maintain control or ask for improvements?”
  - “How do I feel respected and let my home support worker know s/he is valued?”
  - “Do I have to pay if the job is not being done properly?”

- “How do I manage worker turn over because they tell me the pay is too low?”
  - ‘What do I do if I find things disappearing from my home?’
  - ‘What do I do if I feel I am being taken advantage of?’
  - ‘What do I do if I am being abused by my worker?’
  - ‘What do I do if the worker calls in sick?’
  - ‘How do I know what is best for me; going through an agency or self managed care?’
  - ‘I train my own home support workers but now with the huge turnover in staff I have to retrain over and over. How can I continue to cope with this?’
8. Self managed home support works well for some consumers.
- One person commented, “I get to choose who comes into my home and who I spend my time with.”
  - Those who report the most satisfaction with this arrangement have a contract with a clearly articulated job description for the worker, which is presented at the interview phase. This way both the consumer and the worker understand and can discuss boundaries and expectations before accepting the job/worker.
9. Finding and maintaining the mandatory third party payroll service can be problematic with self-managed home support.
- Consumers report that companies offering this service have closed down, claiming excessive reimbursement times from government agencies for the service the company was providing.
  - “Three times in the last six months I’ve had to change the business that handles the administrative and payroll part of home support. One of the two recommended to me when I started was great until they folded last year due to huge amounts of money owed to them by government. This is a lot of extra work, stress, and time on my part.”



## ***Recommendations***

1. Initiate a comprehensive study that fully illustrates the challenges, diversity, and complexity of home support/home care.
2. Home support workers must be properly compensated for the services workers provide and have access to the Workplace Health and Safety Compensation.
3. Recognize that for most people with a disability home support service is essential and often the only option between living within the community and institutionalization.
4. Keeping people with disabilities out of institutional care is one goal of home support services. To maintain this focus, home support must be visualized using a wide lens of what constitutes support.
5. Key to individualizing service is promoting a flexible system.
6. Acknowledge people with all types of disability may require home support services at varying times in their lives. Home supports must be fluid in nature to respond to changes in need.
7. Know that home support service potentially helps consumers in rural areas to get the support required without relocating to urban areas.
8. Restructure needs assessments so that a truer reflection of the service required becomes more readily apparent. Consumers report too frequently their needs do not fit into rigid assessment criteria.
9. Recognize sometimes people with disabilities are unable to adequately articulate their needs during assessments and may require support to do so.
10. Recognize that superficial system stopgaps, specifically those focused on providing community-based mental health supports, provide band-aid treatments rather than tackle underlying issues.

11. Management of community-based mental health care is not adequate and frequently linked to interaction with law enforcement agencies that are inadequately trained to deal with consumers.
12. Engage the disability community in conversations about home support and training for home support workers. Rubber-stamping home support training, using only medical models of care, is not what is needed.
13. Fund community based workshops that properly inform and train consumers to become managers of their own care.
14. Develop and promote templates for home support best practices from consumers that have success in self managed care.
15. Examine the issues arising from the mandatory third party payroll service. Entrepreneur opportunities could be explored for some consumers to provide this type of service. However, this cannot be encouraged if the pattern is that larger companies could not maintain the service because of unacceptable delays processing government reimbursement.