

Self-Management and Supported Decision Making

Our Search for Best Practice

Introduction

The Public Health Agency of Canada funded a project initiated by the Kendrick Report Coalition (KRC) to investigate best practices for two alternatives to traditional forms of disability supports: self-management and supported decision making. Evaluations of these program options indicate that they consistently yield positive outcomes for government funders, communities and individuals compared to traditional agency directed systems or institutionalization.

The purpose of this paper is to introduce you to these programs; define principles and practices that we have determined constitute best practice; describe what we found through consultation within Nova Scotia; and list five policy goals that have emerged from our research.

Policy Goals

The Kendrick Report Coalition recommends that both the Nova Scotia Department of Health and Department of Community Services:

- 1. Establish a mechanism for ongoing consultation** with the community. The perspectives of program users, potential users, their families, service providers and community groups must be considered prior to and throughout the implementation of self-directed programs.
- 2. Follow the best practices** outlined within this document in the design and implementation of self-management and supported decision making programs.
- 3. Recognize the full potential of self-determination.**
- 4. Entrench programs in policy**, thereby ensuring that self-management or supported decision making is available to all who qualify.
- 5. Ensure resources are available** to maintain effective program infrastructure and supports. Training and on-going support of program participants are critical elements for success.

Definitions

Self-Management (SM)

- Enables an individual with a disability to directly control the resources that are available for his/her supports.
- Self-managers recruit, train and evaluate staff providing supports.
- Self-managers are responsible for the bookkeeping and reporting that is required as an employer.

Supported Decision Making (SDM)

- Enables individuals who require assistance with decision making to receive individualized funding.
- Individuals choose a support network of family members and/or friends to assist them with the process of managing their supports.

Underlying Values

The philosophy of self-determination is based on the right of persons with disabilities to make their own decisions regarding all aspects of their life, to live with dignity in their chosen community, and to control the services and supports provided to ensure equal opportunity. All persons with disabilities, including those with high support needs and the frail elderly, have a right to experience “dignity of risk” by being able to make decisions (and mistakes), and be the “authors” of their own life stories.

Both self-management and supported decision making programs place the individual at the center of all decisions. The role of professionals is to provide information, resources and direct care supports.

Best Practices Summary

Our list of best practices for self-management and supported decision making evolved from an extensive literature review of programs in Canada and internationally; discussions with individuals in five town hall meetings held across the province; and the evaluation and analysis of the Steering Committee, who collectively represent a wide range of service users.

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| <ol style="list-style-type: none">1. A continuum of supports2. Entitlement to supports3. Choice and control4. Independent person centered planning5. Self/co-assessment6. Individualized funding7. Program infrastructure8. Safeguards9. Single point of access10. Transparent appeals process11. Effective management of human resources12. Accountability |
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1. Continuum of Supports

Funding and support options need to reflect changing capabilities and needs. Programs must provide a continuum of support options to enable self-determination. At one end of the continuum are self-managers who are able to receive individualized funding and manage their supports independently. At the other end of the continuum are individuals who have a system of formalized decision-making supports, which enables them to access individualized funding. Persons who require support may be situated at any point along this continuum, and may also move along the continuum – towards self-management or supported decision making – based on the nature of their disability, changing needs, age and functional abilities.

2. Entitlement

Access to political and economic resources needs to be recognized as a civil right. The report developed by the Federal, Provincial and Territorial Ministers Responsible for Social Services, called “In Unison 2000: Persons with Disabilities in Canada”, presents a vision for Canadians with disabilities of full citizenship based on the concepts of equality, inclusion, rights and responsibilities, and empowerment and participation.

Western European countries serve as model examples of community based disability accommodation entrenched in legislation, which includes: non-means tested attendant support, choice over who provides support (including family members), direct payments, accessible housing and funding for assistive devices.

3. Choice and Control

Evaluations of self-management and supported decision making programs found that having choice and control in attendant services produced the following positive outcomes:

- Better health outcomes and fewer visits to hospitals
- Increases in employment and income
- Healthier and less stressful family relationships
- Personal feelings of efficacy, empowerment and capacity building
- Higher self-esteem
- Increases in community involvement

“My son is in university. He wants to live in residence like other kids his age. He doesn’t want to live at home or in an institution and he certainly doesn’t want his parents taking care of him.”

(Town hall participant in Port Hawkesbury)

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Individuals want choice and control in:

- Access to services and information
- Identifying their support needs
- Choice of residence
- Choice of workers including family members
- Negotiating flexible arrangements to support employment and leisure

4. Independent Person Centered Planning

Support begins in the planning stages and needs to involve the individual, family and friends. Planning should:

- Address the whole life of the person
- Include wants and needs
- Provide ongoing planning assistance
- Be independent from funding and service providers

An independent planning mechanism is essential in enabling individuals to address their identified needs, and has been indicated by evaluations as the most important component of successful programs (Lord, 2000). For example, brokers, microboards, and community organizations can all provide planning assistance that is separate from funders and service provision.

5. Self/co-assessment

Self/co-assessments or “self-portraits” involve the family and support circle; and respect the dignity and rights of persons with disabilities.

“I don’t like the word assessment. What about self-portrait or self-expression?”

(Town hall participant in Kentville)

A unique feature of the Ontario self-management program delivered by the Centre for Independent Living in Toronto (CILT), lies in the selection process which emphasizes self-assessment by having individuals define the types of services required, create budgets and demonstrate self-management ability. Selection committees of three persons, two of whom are self-managers or have used attendant services, review applications.

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Individuals felt that assessments should be:

- In plain language
- Individualized
- Based on wants and needs
- Holistic (focused on all aspects of a person’s life)
- Used to inform the provision of flexible services, and seamless supports between life transitions

6. Individualized Funding

A best practice model of service provision based on individualized funding has the following components:

- Is negotiated individually based on holistic person centered planning
- Includes adequate funding
- Directly allocated to the consumer
- Is secure, and not means tested

Individualized Funding

(Continued)

Evaluations indicate that self-management and supported decision making program options may be more cost effective than traditional home care or residential options. Lower costs are attributed to the following:

- Administrative costs are absorbed by consumers themselves or paid through a small increment to funding
- Consumers are able to create flexible arrangements that make more efficient use of attendant hours
- Workers are trained to perform tasks that traditionally may have required a more costly service or skill sector
- Individuals set up flexible arrangements with neighbours, family and friends who do not require the types of wages and benefits agency workers require

Pay people directly?

Individuals accessing direct funding manage their money properly and costs are less than traditional systems of care

Evaluations of self-management in Nova Scotia, Alberta, Manitoba, and Ontario and in the United States (Cash and Counseling) found that persons managed funding and book keeping properly.

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The Independent Living Resource Centre's self-managed attendant services pilot and Support Services Group Co-operative are initiatives in Nova Scotia that have enabled persons with disabilities and their families to access individualized funding for community-based supports. Both of these programs were indicated by Michael Kendrick (2001) as examples of how governments can "unbundle" existing funding and re-allocate these funds in creative and empowering programs.

7. Program Infrastructure

Evidence suggests that when individualized funding is successful the proper infrastructure to support persons with disabilities and their families is provided.

Effective infrastructure (involving persons with disabilities, families and advocates in the planning and implementation of services) has the following features:

- Access to ongoing technical support and training, when required
- Ongoing planning assistance
- Financial management supports if individuals choose to self-administer their funding

In Australia 70% of all supports for persons with disabilities are provided by friends and family members. Understanding this, Local Area Coordination (LAC) provides support and services to the person with the disability and their family in their local community. The program encompasses a multi-tiered approach to service provision including case management, advocacy, family support, community development and direct funding.

8. Safeguards

Research indicates that training in self-advocacy and assertiveness is important for consumers and that workers benefit from training in principles of self-determination and independent living.

For persons who are self-managing funding and supports, safeguarding is their responsibility. Consumer supports such as ILRC's can provide an invaluable resource for persons in this regard by offering training, peer counseling, and advocacy. For persons in supported decision making programs, family members, friends and counselors can provide safeguarding.

In the United States, Cash and Counseling Demonstrations enable individual to access direct payments for disability supports. Positive outcomes have been attributed to counselors who provide training, support, fiscal assistance and monitoring. Persons with developmental disabilities are eligible for direct payments but must appoint representatives.

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Persons indicated a need for support and training in establishing appropriate safeguards; e.g., criminal record checks, attendant rosters. They also indicated safeguards need to be individualized, and involve the community and support system of the individual.

9. Single Point of Access

Too many departments, unclear guidelines and lack of information have been roadblocks to access for many individuals who require support. A single point of access for determining eligibility, negotiating funding and planning assistance has been identified by program evaluations as an indicator of positive outcomes for service users.

Local Area Coordination (Australia), Brokerage (BC and Windsor, Ont.), Self-management (Ontario), and Individual Quality of Life (Toronto) incorporate infrastructures that serve as a single point of access for individuals applying for and receiving individualized funding.

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- Services should have adequate resources and consistent standards
- Public education should inform individuals about existing programs
- Communication should be accessible and in plain language
- Access should be standardized across the province

10. Transparent Appeals Process

Service users need recourse if they are dissatisfied with decisions about funding and support arrangements. A transparent and accessible appeals process is instrumental to empowering individuals who are accessing individualized funding.

Sweden offers service users a three-tiered legal process if they are dissatisfied with the supports they have negotiated with their local municipalities. Research indicates that the courts in Sweden favor the civil rights of persons with disabilities ensuring they have adequate accommodation.

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Individuals consistently indicated they want access to third-party mediation when decisions about funding and supports are made.

11. Effective Management of Human Resources

Persons who need support, and their workers, want the same things: “Dignity, respect, decent wages for their work, a sense of autonomy, participation in the planning and delivery of services, a route out of poverty, health benefits, education and training, a chance to reach their potential and a home of their own” (Ebenstein, 1996:111).

Services are based on “supply and demand”. Flexible funding enables persons to purchase the services that best suit their needs, whether from a family member, neighbour, existing agency, independent worker or specialty service. When services are unavailable consumer demand has the potential of stimulating new services. A new source of workers emerges when consumers hire family, acquaintances and neighbours, which has been cited as one way of addressing worker shortages in home care.

Informal care arrangements characterize the home care sector in Europe, where persons and their families receive money directly for disability supports. Research indicates that 70% of this funding is paid to family members, or becomes a part of the household budget to defray disability related expenses and reimburse family members for work.

Our research indicates that the rights of workers within a system of individualized supports and funding have to be protected. Adequate pay, benefits and workers compensation have all been indicated as being important to maintain a properly trained and consistent workforce.

Independent workers prefer employment in consumer directed systems because they feel safer; there is less conflict and red tape; they appreciate and support the tenets of independent living; and enjoy the benefits of being an independent worker, not tied to a particular agency.

Research also indicates that workers need to be trained and educated about the benefits of consumer direction for persons with disabilities as well as their rights within these systems.

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Persons in Nova Scotia want:

- A well paid work force with benefits
- A grievance procedure for workers
- Training for workers and service users in the principles of consumer direction
- Training for service users and their support networks in the responsibilities of managing funding and staff support

12. Accountability

The principles of self-determination acknowledge that individual responsibility for the management of individualized funding requires the establishment of fair and effective accountability mechanisms. The government departments which provide individualized funding are accountable to the general public for the expenditure of tax dollars. At the same time, people with disabilities must be fully informed of their responsibilities to report on the allocation of funds, and also must be supported in the administration of reporting requirements. Consumers also do not want to be burdened with excessive or unnecessary reporting and monitoring.

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