DISCUSSION PAPER - "TAKING THE NEXT STEPS"

AN ANALYSIS OF THE SYMPOSIUM AND WORKSHOPS 1999 - 2001

BACKGROUND

The juxtaposition of the terms "aging" and "developmental disabilities" is a new phenomenon in the service system. It is the result, not only of the aging boom, but also the unprecedented longevity among people with developmental disabilities. The phenomenon creates new challenges for caregivers, planners and funding bodies.

This paper presents the ideas of service providers, unpaid caregivers, planners, researchers and funding Ministries as they explored the issues surrounding aging and developmental disabilities in a series of workshops across Ontario from 1999 to 2001. Their thoughts were collected at the Symposium on Aging and Developmental Disabilities held in Toronto in 1999 and four regional workshops held in Kingston, London, Orillia and Thunder Bay in 2000 and 2001. The synthesis of participant dialogue presented here is complemented by summaries of papers presented by Tamar Heller and Matthew Janicki at the Toronto Symposium. The entire document offers a picture of what we already know and suggests avenues for further work in responding to the aging boom among people with developmental disabilities.

Participants in the aging and developmental disability regional workshops being planned across Ontario for 2005 and 2006 will find this document useful as a starting point for further dialogue and partnership building.

PARTICIPANT DIALOGUE - KEY THEMES

Proceedings from the symposium and workshops were analysed to identify recurring ideas running through participant discussions. Four key themes emerged from this analysis:

1. Partnership – working together to identify solutions and plan implementation.

2. Learning – through research, education and multiple training strategies.

3. Best Practices – testing models and identifying best practices relative to supporting older adults with developmental disabilities.

4. Policy and Planning – working with planners and policy-makers to create a new paradigm of support.

PARTNERSHIP

It is noteworthy that participants in the symposium and workshops did not question the need for a partnership between the sectors. Their discussions focused on the rationale for partnering and how a working relationship could be established and strengthened. This readiness to partner is evident in comments from participants such as:

> "Inter collaboration between service providers must be enhanced."
>
> "Cooperation and coordination between existing service providers regardless of funding source."

Delegates see partnering as not merely a nice idea but of strategic importance:

> "Collaboration and partnership can reduce duplication and increase service levels."

While there was no specific partnership model put forward, participants did identify some important points for building a working relationship. An effective partnership is one in which there is participation from a wide range of actors:

> "Partnering should encompass provincial (inter-ministerial), federal (interdepartmental), corporate, agencies, community organizations and municipal governments."

And where there is buy-in from the heads of organizations:

> "Collaboration needs to start at the top."

Moreover participants stressed the need for the provincial government to be part of the collaborative process through cross Ministry planning processes and joint projects between the Ministry of Health Long Term Care and the Ministry of Community and Social Services.

Partnership – Questions to Consider

1. What do we need from a partnership between long term care and developmental services? What are the success factors?

2. What specific steps can we take to create/build a partnership in our community(ies)?

3. Have we invited all of the long term care and developmental services players / stakeholders within our region to the table? (service providers, planning/coordinating bodies, Ministry of Community and Social Services, Ministry of Health and Long Term care, municipal government, academic community….)

4. What can our regional cross sector planning group and OPADD do to support local partnerships?

LEARNING

The need for learning among caregivers, service providers, planners and legislators received significant attention from participants. The learning requirements of the two sectors were highlighted through comments such as:

> "Low knowledge of how people with disabilities will age."
>
> "Vastly different cultures of the two service sectors."
>
> "Long Term Care and Developmental Services caregivers have limited knowledge of one another's areas of expertise."
>
> "LTC residents have no experience with the developmentally disabled."
>
> "…provide medical training to staff."
>
> "Community service providers have a lack of knowledge about how to deal with developmentally challenged persons e.g. homemakers, Personal Support Workers, nurses – fear due to this lack of knowledge can be a problem."

The knowledge gap was seen as a problem that could mitigate against effective support from the sectors. Participants made a number of suggestions on how to shrink the knowledge gap including the adoption of various cross sector training strategies, curriculum renewal by learning institutions and the use of technology:

> "Information-sharing."
>
> "Cross training."
>
> "Cross secondments."
>
> "Cross education to allow the services to work together."
>
> "Changing the curriculum in colleges."
>
> "Curriculum that includes all elements from both developmental disabilities and long term care."
>
> "Joint Diploma Program."
>
> "Placements."
>
> "…better use of technology such as videoconferencing and internet use..."
>
> "Up to date information is needed on a web site."

Discussions about the knowledge gap identified the need to include the education sector in the solution:

> "Specialized service providers (should) reach out to universities, medical schools, occupational therapy programs, physical therapy programs, etc. to partner and educate."

> "College/university credits for workshop participation."

Participants also pointed out the learning needs of various actors:

> "Parents need to be educated (about) what supports are needed."

> "Educate Regional Geriatric Programs (RGP's)."

> "Psychogeriatric consultant will be a bridge; use this in training; involve General Practitioner and specialist – incorporate into Alzheimer Strategy.

Discussion highlighted that new knowledge must be sought to equip the sectors to deal with the challenges ahead:

> "Research – medical, health."

The discussion on learning indicated that much of the information is already here and simply must be made available through cross sector dialogue and training strategies. However, the education sector is an important ally in the learning piece both in terms of curriculum change and for its capacity to facilitate research pertinent to aging and developmental disabilities.

Learning – Questions to Consider

1. What are the learning needs of caregivers in each of the sectors?

2. How can each of us obtain first hand knowledge about the other sector?

3. What can we do to put cross sector training and secondments in place within our communities?

4. How can we engage in a dialogue with the education sector to facilitate curriculum renewal and cross sector placements?

5. How can we use technology and the OPADD website to provide for some of the training/information needs of caregivers, planners and others?

BEST PRACTICES

Participants identified several issues that must be addressed in the pursuit of best practices:

"The fear of death."

"Ageism."

"Medicalization and pathologizing of the aging process."

"Differences in philosophy between medical model and social model."

"Myths about LTC image as an institution."

"Acknowledge that we (LTC) provide excellent services."

"Concern re re-institutionalization."

Discussions identified strategies for developing best practices to support older adults with developmental disabilities:

"Philosophical values, common understanding of client centred objective."

"Standards of care."

"Mandatory accreditation."

"Continuum of care."

Participant dialogue on best practices reinforced the need for cooperation and common processes between the two sectors:

"Common shared assessment."

"Transition support."

"Inclusion, integration into existing seniors programs."

"Cross sector project collaboration."

"Systemic protocol: developed between Ministries."

"Service protocols: developed between agencies."

While cooperative strategies rated highly, participants stressed the need for a range of supports to be made available to older adults with developmental disabilities:

"Increase the variety of alternatives where people can be supported."

"Housing options – units within existing seniors housing."

"Clinical services."

"Assessments, baselines for aging adults."

Participants also noted the need for best practices to reflect the preferences of older adults with developmental disabilities:

"Self-advocacy and awareness of rights."

"Remember the wish of seniors to age in place."

And that the needs of families/caregivers should form part of the response:

"Support to families/caregivers."

Finally, the attainment of best practices will have implications for timely access to services:

"Arbitrary caps on services need to be re-evaluated.

Best Practices – Questions to Consider

1. What can we do to overcome our fears about aging and dying?
2. What can we do to overcome our pre-conceived ideas about the other sector?
3. How do we reframe our thinking about best practices so it focuses on helping people adapt to the aging process and maintain quality of life?
4. What kinds of cooperative processes and projects can we initiate to test and confirm best practices?
5. What would the ideal model of transition planning look like?
6. How do we work the seams between the two service sectors so it is easy for individuals and families to access appropriate supports as they need them regardless of which sector provides it?
7. What can government do to support the development of best practices that help people adapt to the aging process and maintain quality of life?

POLICY AND PLANNING

Participants stressed the need for more information on which to base policy and planning decisions:

> "Need research on who they are, how many, where they are, the effects of aging on various disabilities and how these numbers affect the health care system."
>
> "Need data about people and services."
>
> "Communities must identify their population by age and primary and secondary diagnosis for proactive planning."
>
> "Service providers should be aware of the entire local resources and how to access them."
>
> "Pilots / tests."
>
> "Task Forces."

Workshop discussions pointed out that effective planning will require policy-makers/legislators to be engaged:

> "Reach the policy makers."
>
> "Planning and coordination between government sectors at the upper levels."

And that service provision by the sectors would necessarily require more integration:

> "One continuum and one access point."
>
> "CCAC intake/mandate for both systems."
>
> "CCAC threshold – the bar is too narrow, too high."
>
> "Individualized MOH/MCSS planning protocol."
>
> "Developmental disability agencies should have natural links to other sectors."

Planning issues covered a wide range of service delivery issues and factors such as:

> "Individualized planning."
>
> "Accessibility."
>
> "Tipping Points, when to move to a long term care home?"
>
> "Multiplicity of service providers potentially involved with one family…"

"Outlaying communities have larger gaps in service provision due to geographic barriers."

"Rural issues related to distance, transportation, time and cost, reaching families because of isolation."

"Need to broaden the level of discussion to housing, transportation, municipal government, families."

"Aging with dignity."

"End of life planning."

Participants acknowledged that planning will require consideration of resource allocation issues:

"Funding of training and ongoing funding for planning of inclusion."

"High staff turnover is a Ministry issue to resolve."

"Funding for transition to long term care."

"Increase service maximums and change eligibility criteria; requires more funding."

"Cross funding; i.e. provide facilitator for planning process."

Finally, planning and policy must not only take place at the level of systemic cross sector processes and government but must also be part of the work within individual organizations:

"Establish policies."

"Board of Directors need to be aware of the issues; i.e. the needs of aging clients and the resulting services, programs, etc.; need to be specified in board values, mission statement."

Policy and Planning – Questions to Consider

1. What sources of research information are there that we could tap into?

2. How can we obtain and maintain data about the numbers of people with developmental disabilities and their needs?

3. How do we dialogue with CCAC's to ensure older adults with developmental disabilities are considered equally with all other seniors?

4. How do we ensure a continuous dialogue with policy makers on the directions we are pursuing and the regulatory support we require?

"AGING & DEVELOPMENTAL DISABILITIES: EMERGING MODELS OF SUPPORT" TAMAR HELLER

One quarter of the population will be over the age of 60 years by 2030

Longer lifespan is accompanied by a longer care giving period.

Philosophy of support to people with developmental disabilities has evolved from a segregated and institutional model to one of community membership.

Service delivery under the community membership model includes:

- Greater commitment to family and community as resources.
- Emphasis on human relationships and friendships.
- Individualized life plans and person-centred programming.
- Choice and control by people with disabilities.
- Emphasis on quality of life.

Alternative concepts of serving older adults with developmental disabilities are emerging:

1. Segregated model – programs developed for the population within the DH sector.

2. Integrated Model – integration of older adults with developmental disabilities into the system of seniors' services and vice versa.

3. Community membership Model – Individualized programs that could include all of the above as well as integration into other community programs.

The support needs of older adults with a developmental disability will require:

- More residential options.
- Day services and retirement programs (e.g. seniors centres, adult day care, pre-retirement education).
- Family support programs.
- Training in choice-making to empower individuals.

Assistive technology offers potential for older adults with developmental disabilities but has not been widely used.

Most successful models are likely to include both aging and developmental disability services with coordination across the two systems.

"PUBLIC POLICY AND SERVICE DESIGN"
MATTHEW JANICKI

How can public policies that apply to needs of an older population be made to apply equally well to older adults with intellectual and developmental disabilities? Such an agenda should consider demographics, changing ideologies, social practicalities and the evolving needs of older adults with developmental disabilities as they age.

Doubling of older adult population by 2030 coupled with increased longevity will place new demands on health and social policy and services. New and clearer public policies and innovative service designs are needed to sustain the skills and functional abilities of older adults with developmental disabilities and promote staying healthy and content in a community environment.

Planning for older adulthood includes:
- 3rd age (generally ages 50 to 75) - transition from employment to retirement
- 4th age (generally over 75 years) - evidence of more pronounced physical decline and increasing health care requirements.

In societies without a tradition of government support for older adults with disabilities the population is excluded from the greater community; society has not made accommodations relative to accessibility, transportation and employment; support staff are unfamiliar with the aging process; medical practitioners are poorly informed. In nations with dual systems of support for older adults and people with developmental disabilities a debate is emerging as to whether supports should be available within the disability community or from the system of services for all older adults. Some debate is coloured by a general aversion to old age even by well-meaning disability advocates. The model of successful aging includes having the capacity to maintain one's physical and cognitive health, maintain control over life choices and give of oneself in a manner that is fulfilling and productive. A range of support strategies must figure in addressing these aspects of healthy aging.

Issues of policy and service design arise from a number of factors:

1. Some disability-related conditions do not have any significant effect on the aging process while others cause new or "secondary conditions."
2. Increased numbers of older adults puts pressure on the system's already limited capacity to provide assessments yet regular assessments should be an integral part of every older adult's life.
3. End of life support will raise new legal and programmatic issues
4. Aging of people with developmental disabilities requires that service providers adopt policies and ensure access to retirement planning and retirement options.
5. The capacity of service providers to support "aging in place" given the range of needs among older adults – the need for appropriate alternative care situations requires a great deal of scrutiny.
6. The ageism of some service providers may contribute to premature referral to a nursing facility.
7. Family caregivers are aging themselves; service limitations and funding regulations often mitigate against flexible support to family caregivers.