

KACL Discussion Paper on Transforming Services in Ontario for People who have a Developmental Disability

November 17 2004

Background and Purpose

On October 18, 2004, the Ontario Budget announced that “The Province will be transforming services for people who have a developmental disability in order to create an accessible, fair and sustainable system of community-based supports”. Following this announcement, the Ministry of Community and Social Services invited a group of provincial organizations to form the “Joint Developmental Services Sector Partnership. The Partnership Table in turn prepared a paper to raise questions that were intended to help people share their own ideas. This paper will commence with an attempt to provide some input to the questions asked and then at a later point in time will redirect at specific what changes government should adopt.

A 7 person parents group met on Wednesday October 27, 2004 to discuss the paper. The Executive Committee in its capacity as a Strategic Planning Committee discussed the paper on Thursday October 28, 2004. Senior Staff discussed the paper on October 20th and November 3rd. The Board had a discussion on November 4th. On November 6, 2004, 3 Broad members and the Executive Director attended a meeting hosted by Community Living Ontario to give input on the paper. This paper will be used as a discussion paper as the Board creates its response to the Government document when published. It will be posted on the Association’s website at www.kacl.ca soon after November 6th, as soon as the feedback from that meeting can be assimilated. The Association also had the benefit of a November 14 2004 paper prepared by Sheila Simpson & Associates for OASIS of which the Association is a member. Any member who wishes to get a copy of the partnership paper should call KIM BOUCHER 467-5228 at the central office.

Vision /Principles.

Vision Statement: Persons with disabilities participate as full citizens in all aspects of Canadian society. With commitment from all segments of society, persons who have a developmental disability will maximize their independence and enhance their well being through access to

required supports and the elimination of barriers that prevent their full participation.

There appears to be near unanimity that the vision statement is “ambitious”, “lofty”, “worthy” and that our Association should look at incorporating it in some fashion or other into its own statement of ideals. Concerns were also expressed that the vision may be mere platitude: a lot of work will be required to change it from a platitude to a generally accepted attitude. In balance, the largest number of those who gave input to the KACL process, felt that it was worthy of respect and should set a goal to which KACL should strive.

Answer to Questions on Preliminary Partnership paper

Question 1: What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?

The First question listed in the Discussion Paper was, “What should be the role and responsibilities of different parts of society in supporting individuals who have a developmental disability. Further on some of the “parts” of society were identified to include, “Individuals who have a developmental disability”, “Families”, “Governments Service Providers”, “Other parts of society, such as business, faith-based communities and cultural organizations, service clubs and voluntary organizations”.

KACL has already addressed some of the questions in a paper entitled “Shared Responsibility [\[1\]](#) Paper” and “Approaches to individual funding” . Both papers had their births in the 1993-94 eras, with minor revisions thereafter. The following sections of those papers identified policy of the Association which appear to be relevant to the first question:

All people in Ontario are entitled to an equal assurance of life opportunities in a society based on fairness, shared responsibility, and personal dignity for all. Society

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has a responsibility for the well being of all its members . The support that society provides is not to be understood as a gift or privilege, or as charity to the disadvantage. Rather it represents a right to which all members of society are entitled.

Individuals have a responsibility to become, with support where necessary, as self-reliant as possible and to contribute to community life. We see the obligation of the individual to take responsibility for his or her own life as the other side of the coin of mutual responsibility. If the whole of society has a responsibility for individual well being, then individually, there must be a responsibility for society as a whole. This translates into each person making his or her unique contribution to society's social and economical well being.

Individuals have a responsibility to contribute to society to the extent that they are able.

As a condition of being provided supports, consumers or their families are required to apply for supports and in return for such supports and services must enter undertaking to participate in planning with KACL for their child's future, including the provision of alternative supports which provide natural or less costly supports.

Existing consumers and their families must seek natural supports and alternatives less costly supports. They must co-operate in securing the most efficient and effective use of resources possible and the greatest sharing of resources among all persons with special needs in the geographical area served by KACL. If they refuse to do so they may be required to assume a greater burden of support.

This to us does not sound strikingly different than the concept of full participation or the concepts identified in the Federal-Provincial Government Agreement entitled "In Unison".

Also relevant is the Association's service delivery principle entitled:

3(a). Principle of Family and Community Involvement

Ensuring the right of all persons with special needs to participate in all aspects of living, learning, working and playing is a shared responsibility among parents, siblings, friends and the association (including its paid staff and volunteers). All must be encouraged to be actively involved in the life of such persons.

The parts of the paper that might be directed to the role and responsibility of families might be considered more appropriate to the nature of the responsibility of the families when it comes to applying for assistance from the province. While the Province and Federal Government do place legal obligations on families and penalties for failure to meet such obligations, generally families represented by KACL do not see their actions as motivated by “responsibilities” but rather by “relationships”. Families do not support family members because of obligations or “oughts” but rather because they want to.

The Shared Responsibility paper referred to above does include the following comments:

“Consumers who have obtained the age of majority (19 in Ontario) are and should be treated as independent adult and should not be beholden or be required to be beholden to their families. An alternative view is that families bear a moral responsibility to assist their children under the age of majority and dependent children over the age of majority and should be required to fulfill such moral responsibilities before "dipping into the public purse".

“The Association adopts the position that resources available to the consumer and his or her family should be one, among many factors, considered in allocating support resources to the consumer and family.”

The role of the family continues to come under scrutiny and at times attack from several quarters. In the society in which we grow up, there exist a fairly stable set of values and expectations that play a major role in the formation of our self and our sense of identity. What constitutes a freedom or an infringement is largely determined by the cultural background. Practices in one culture even as insignificant as who washes dishes may be regarded as a sign of respect in one and a one of self-denigration in another. There is a tendency in western culture to invoke a freedom of choice regardless of the setting in which one finds oneself. While there must limits to what unrestrained conduct in private is permitted reliance to a large extent must be by way of social sanction to preserve the strengths of the family institutions.

But individuals should never be left isolated either entirely alone – on in very small segregated social units. There must be a careful balancing of the needs of the individual for autonomy,

privacy and choice free from external constraint and protection and support that can only come in a social context. The notions of ideas such as “equality”, “impartiality” or “fairness” are deeply antagonistic to the values of love and benefice espoused by family members for their own. As suggested The Honourable Mr Justice Charles D. Gonthier in a paper entitled Liberty, Equality, Fraternity, The Forgotten Leg of the Trilogy, or Fraternity: The Unspoken Third Pillar of

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Democracy” You can’t have equality and liberty without fraternity. Such fraternity must extend to and from the community.

Role and Responsibility of Governments Service providers

KACL is both a “government service provider” as well as an association of members consisting of consumers, survivors (Term chosen by individuals served by our Community Mental Health Support Services program funded by the Ministry of Health) families, friends and supporters. In the first context the Association acts as an agent of government. In the context of providing services as an agent of government the following statement of need was drafted:

Long-term predictable financial funding for services must be available that realistically meet the costs of respite, day programs and residential needs to allow individuals full participation in society.

There were also discussions on the role of planning and concerns expressed that attempts of government to separate planning from implementation were artificial, counter productive and inefficient. The view was also expressed that planning provided by single points of access was not necessarily of the personal and intensive nature necessary to provide a healthy basis for day to day services. Day to day services should be provided that assist the consumer to recognize his or her “vision” or discover the consumer’s and family’s dreams, desires and aspirations and to establish long term goals.

There is considerable concern that Government’s attempts to provide supports from a regional basis will draw Government service providers away from their membership's desires to have their children live learn work and play in their home communities. There is a fear that government

needs for centralized control runs counter to the requirements of local approaches when asking for community response. Such community for our members is Kenora and surrounding area.

Role and Responsibilities for other parts of society, such as

Business

This section generated more questions than answers. What is meant by a “Role” and “responsibility”? Role is assumed to be a social term implying that there are certain expectations of an individual because of the position that he or she occupies. For a group of individuals such as business, cultural, religious, fraternal or service clubs there might be expectations or there might be organizational statements of roles and responsibilities. Individuals and groups may have legal responsibilities such as compliance with Human Rights Legislation; some legal obligations may translate into economic determinations as in the duty to accommodate. For many individuals who commented to KACL, this is an existential or moral question answered only by the individual or group. A general point of discussion under this section is a questioning of the question. Should the question be broader than just what is the “responsibility” of the other parts of the society? For example, what is it that keeps consumers and survivors out of full participation in the other parts of society mentioned? The answer seems to be best summarized elsewhere in terms that it’s in the interest of those we served to be known, understood and appreciated by as many individuals as possible and that such familiarity, awareness and inclusion would generate the “compassion”, “empathy” and friendships necessary to permit full participation to be an achievable goal: See Question 7 below.

Generally discussions around the role and responsibilities of business to the disabled have produced discussion around the role and responsibility of government in regulating welfare than the actual role and responsibility of business itself. Some comments discussed ideas of government making certain sectors more affirmative action oriented e.g. collecting from parking meters in Europe. There is general agreement that businesses – particularly small business owners are in business to make a livelihood and a buck – and that there is nothing wrong with that. While shallow discussion may elicit negative quip against certain businesses there appears to be a general acceptance that business can provide greater efficiencies and choice than a planned economy and that businesses should not be required to hire our consumers at any rate above which there business interests or sentiments dictate. The general view expressed that education and familiarity go further than coercion in the successful generation of employment opportunities.

Businesses are subject to the Human Rights Act and it is their duty to respect that act including the duty to accommodate.

Faith-based communities -The Church

One long-time faithful member of the Association expressed disappointment with the organized church. But, “People should not confuse church-anity with Christianity.”

In John McKnight’s *The Careless Society* exclaims “It is not enough... to ask whether someone says he or she is serving Christ. There are bad and good servants”. Bad servants conquer, dominate, exploit and control. They become lords rather than servants. McKnight questions whether the human reality is always to make servant hood into lordship. Christ concluding remarks in St. John’s reporting of the last Supper was to call his disciples friends rather than servants. McKnight concludes:

Perhaps beyond the revolution of Christian Service is the final revolution, the possibility of being friends. Friends are people who know, care, respect, struggle, love, justice, and have a commitment to each other through time.

Why friends rather than servants? Perhaps it is because He (Christ) knew that servants could always become lords but that friends could not. Servants are people who know the mysteries that can control those to whom they can give “help”. Friends are people who know each other. They are free to give and receive help.

Could the Church become a place where persons with disabilities might find friends?

Cultural organizations

As in every other sector, when someone invites persons with handicaps into a cultural organization they enter. Entry fees or ticket prices are at times a problem. At other times having an interested friend is a requirement.

The Cultural Organization may provide the context which determines whether consumers like other members of the organization have a common interest. However an organization may be welcoming or not. For example, some Robbie Burns' organizations still discourage the involvement of women in such organizations as they did in the Bards own period (1758-1796). Other similar organizations have evolved and now encourage the inclusion of women. Some cultural organizations and service clubs require further evolution.

Service clubs and voluntary organizations?

Roles and responsibilities are, by and large, self determined. However, courts have entered the fray at times with decisions that affects the club as in when they have declared that Human Rights legislation requires non-discrimination in membership on the basis of gender. One Service club might accept one service goal which another chooses to ignore. Integrity of the individual and organization requires commitment to self accepted responsibilities and expectations voluntarily assumed. Again social networking that develops within such clubs may have a considerable impact on the meaningful full participation of an individual in his community.

Quite apart from the lack of invitation, membership fees tend to make membership prohibitive.

What changes are necessary to encourage the above players to work together to carry out their roles and responsibilities?

The following were suggested:

Greater compassion.

Greater interaction and familiarity will generate greater understanding.

Greater comprehension of the reasons why inclusion is necessary.

Those consumers will be known by the community and protected by the community and not seen as sub-human or only worthy of protection rather than inclusion.

The world of the individual is a world constructed from experience – a person who has not experienced the world or alternatively a small part of it will develop different maps that a person who has experienced a more balanced presentation.

Greater social networking – clients be known before people will feel obliged or willing to help – they will help when they see the consumers as one of their own.

2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

Transition into and out of the school system:

Decent funding of service providers to assist in visioning, vocational supports, move to greater independence, more meaningful Co-ops

-Into employment and through changes in employment

More dollars for job coaching and supports,

-Into senior years

3. What supports and services that are currently available work well and should be built on for the future?

- Lifesharing is most popular option but requires a higher quality staff to administer program

KACL is supporting an aging population of adults whose children once lived large institutions and who require more specialized support to address their medical needs. Families with young adults requesting support who do not have experience with the culture of institutions are generally requesting non-group home options – either family home or life sharing.

- Literacy and Augmentative Communication – but not enough dollars to support it
- Individualized funding: Issues: Just getting into this.

4. How should a reasonable level of government funding for an individual be determined?

Needs must be reflected in amount but most severely handicapped are not always the most expensive to serve. Full participation requires more than attention “negative” needs. Positive support for dreams, desires and aspirations must also be available.

There is appears to be some agreement that the level of handicap should be a factor in determining amount. There was general discussions as to how any assessment scheme could be devised that would not encourage or force everyone to see consumers in a negative way.

In the Shared Responsibility paper referred to above the view was stated that “... the position that resources available to the consumer and his or her family should be one, among many factors, considered in allocating support resources to the consumer and family.” Such resources previously were talked about in terms of the family. The Association is of the view as expressed in various papers that the resources that should be taken into account and in the negative the lack of resources that should be taken in to account are not only the family but the community. Terms that have become more familiar over the past 10 years since the shared paper was primarily drafted include “social capital”, social networking capacity” and “community capacity”. All such

capacities or lack thereof must be considered before arriving at the appropriate amount of support for an individual. It appears that government are prepared to move clients around regions without regards to the importance of local community supports including family and friends. This is believed to be particularly truer in the North than the South where they simply would not "Get away with it". For example, no one would suggest that some one leave the city of Toronto to move to Kingston to get services but moves 2 to 3 times that distance are commonly suggested in the north, in addition to the total disregard for cultural differences between races and communities.

5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?

Not planning for standardized services but rather personal planning based on the individuals dreams, desires and aspirations and then funds to permit such dreams desires and aspirations to be achieved.

-What do you need? Insufficient funding for Special Services at Home program, More funding for Respite, Day programs, Foundations program, and Residential and alternative residential options supports

-Why do you need it?

Because those we love or those we serve are persons with special needs.

-When do you need it?

Now!

-How long do you need it?

For the rest of my child's life.

Clinical Supports: emphasis in Kenora has been on communications systems, sensory processing expertise and other means to assist individual to better interpret his environment and communicate with those in it. Government emphasis seems to be on control and assessment.

6. What do you think are the priorities the government should address?

Funding for individuals with developmental handicaps must be long-term, guaranteed and adequate to permit continued growth, development and full participation in society. Government must recognize the right of an individual to live and thrive in his own community.

ODSP amounts must be sufficient to cover those expenses that are required for full participation for example: Transportation.

There must be more employment supports staff available.

There must be more funding that supports intensive planning

Individuals receiving ODSP funding need to have opportunities to money without being penalized for income earned over \$160. ODSP funds should be increased for cost of living increases retroactive to 1993.

Families looking after their own children should not be over looked.

Actual Housing is satisfactory but what is required are more staff supports for semi or

independent living and alternative residential options

Day supports particularly need more communication systems training and literacy, social network building

Funding for community capacity building - definitely

Funding and support for innovation: -yes

7. Is there anything else you would like to say about the ideas in this discussion paper, or ideas not included in the paper that you feel are important?

While it is difficult to see progress as a service provider when you are mired in the morass of deficits and waiting lists, KACL believes progress has been made over the broad sweep of time. KACL concurs that the stages that have been identified in the sections entitled “A Brief History of Developmental Services” represent an accurate reflection of the progress in Kenora. The large institution phase for Kenora ended with the closure of North West Regional Centre in 1993. The moving from Mini –Institutional in the community to community over lapped the early period, slowly evolving to the present, with the closure of first Large Community Group homes, Arc Industries, Centralized Day Programs and now the continued close of small group homes in favour of Family Home and Lifesharing arrangements. At each stage, as the rest of the province catches up to KACL it is temporarily dragged back in to the past as the centralized government program attempts to rein KACL into the centralized progress step. Thus for example after having been free from the Homes for Retarded Person’s Act since 1987 it is suggested that we must now conform to some vestiges of it because the act has been repealed for other service providers.

The Association would suggest that services changed primarily be because attitudes of society have changed. Expectations of families, consumers and others that constitute society have changes in terms of knowledge and awareness of consumers and we believe the corresponding greater acceptance. However more work must be completed before full or even substantially greater participation will come.

Obviously it is not by services that KACL’s consumers will receive the alleged citizenship

entitlements – if such exist at all. Nor does KACL believe that statement or legal enactment of legal entitlements will necessarily secure them. KACL suggest firmly that, at the core of society, such platitudes will require a heavy investment in attitude changes. Such attitude changes must start with the school system. As children are truly included and welcomed in schools there may be some hope of attitudinal changes. Schools must be engaged in modeling and teaching the ingredient of good citizenship. One such ingredient, KACL would suggest, is the appropriate compassion for those who through no fault of their own are denied the necessary resources to achieve full participation in living learning working and playing in their community.

Public education at every level should cultivate the ability to imagine the experiences of others and to participate in their sufferings.

Part of the sufferings experienced by persons with disabilities is the ghettoization (as in institutionalization – large or small); the segregation (as in schools); the exclusion; at time and the taunting as absent peers – draw conclusions concerning a person’s humanity from such exclusion; the isolation (as when no means of communication are devised for those who require modified communication systems); the marginalization – from the economic and vocational system of the nation; and in the case of native Canadians, deprivation of culture as they are forced to move from native communities to get any supports from a non-responsive Federal and Provincial government.

While our first message must be that effective citizenship rights ultimately flow not from laws but from compassionate that people with whom they interact, gain laws and institutions play a vital role in changing attitudes. Women have achieved a far greater equalization of opportunity from having had an impact on the legal regulation of human and economic rights and so will ultimately will persons with disabilities. The issue of supports can not be considered in isolation from the legal rights and obligations of intuitions set up by society.

At times those in the Kenora field have a sense of disconnect with those at the Toronto centre. At a time that the partnership Table is talking about the movement to support citizenship by reference to The Ontario with Disabilities Act (ODA) which was passed in 2001 our consumers are having their ODSP cut from \$930 to \$708 as a result of reinterpretation of ODSP guidelines.

Other severely handicapped consumers are being asked to go on waiting lists as they turn 18. It appears that in the near future for new consumers - only the most severely handicapped who came through the Children's aid society system will receive any services at all.

Governments at the federal and provincial levels must pass laws to enhance the legal and economic rights of persons with disabilities. Income Tax laws and other federal laws must be modified to provide economic relief for families who give up employment opportunities to look after children beyond the normal expected duration for children. This may be in the form of enhanced refundable tax credits, contribution deductions to a CPP for non-employed spouse or a registered disability trust.

Portability, without serious reflection of the needs of the North is not necessarily something KACL supports for fear that dollars will move out of north.

Cost of Accountability: How much service do you want to give up for accountability mechanisms?

Get rid of vestiges of Homes for Retarded Persons Act

Individuals must have multiple accesses – not a single access. The single point of access may obstruct an individual from obtaining the supports and services they need.

Importance of personal contact by Personal Planners: Much of the Associations values, culture and ways of conducting itself are very much premised on their recognition of the importance of personal and enduring relationships. A government, a society that attempts to meet the needs of its own purely based on its sense of “obligations” is in serious trouble. This is not to imply other parts do not have responsibilities but rather to suggest that government and Associations efforts should be directed as much or more to the issue of relationships as responsibilities. The

Association has during the past decade began applying this emphasis and finds when it “goes wrong” it is because of its inattentiveness to the issue of relationships.

Themes:

From the above input certain themes stand out:

Commitment Required:

Whether the language be “**an equal assurance of life opportunities in a society based on fairness, shared responsibility, and personal dignity for all**” or “**a right to full participation**” with some greater level of commitment from both levels of government than has here to existed persons with disabilities will continue to exist in a state of less than full social citizenship.

First Nations, Province and federal Responsibilities:

The Provincial and Federal government have simply failed to meet their responsibilities to First Nations citizens with disabilities. Until this situation is rectified such citizens will not enjoy any sense of the good life that should be available to all Canadian citizens. All an Association like KACL can do is to exhort the three levels of government to meet to work on greater co-operation and good government.

Funding:

Long-term predictable financial funding for services must be available that realistically meet the costs of respite, day programs and residential needs to allow individuals full participation in society.

Culture:

The Association believes that culture more than laws determines actual rights and freedoms. Abstract rights and freedoms fail to come to terms with the complex interrelationships between self and society that make up the concept of individual choice meaningful. Culture is local and acquired by association with others in personal and enduring relationships. Government must respect this local culture and individuals should not be forced to move from community to community willy-nilly to meet the abstract views of government “service systems requirements”. Systems exist to serve people – not the other way around

Families Responsibilities and Rights

The Association adopts the position that resources available to the consumer and his or her family should be one, among many factors, considered in allocating support resources to the consumer and family. The institution of the family is an important one and one that must be respected by government and service provider.

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See also Policy analysis Papers on Social Capital and Citizenship at www.kacl.ca [KACL Social Capital Policy Paper.htm](#)

[1]

For existing paper see Policy section of KACL website at www.kacl.ca

[2]

While not identified as such, the first sentence above appears to identical to the first sentence of the “objective” of the social assistance system as identified in a Report entitled Transitions, Report of the Social Assistance Review Committee, Prepared for the Ontario Ministry of Community and Social Services

[3]

(2000) 45 McGill L.J. 567