Holding Our Dreams

A Position Statement on Organizing Support for
Family Groups in the Durham Region[1]
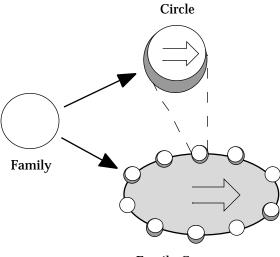
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[1] A position statement defines a proposal for concerned people to build on. It is not a plan to be implemented but a possibility for involved people to develop through their reactions. This position statement arises from the work of a group of parents and staff who have been active in shaping the family network in the Durham Region. The group met on 6-7 October 1998 to review the development of the family network and to consider what will be necessary for the network to thrive in Ontario's changing service and civic environment. John O'Brien facilitated the meeting and drafted this position statement based on a record of the discussion that was carefully reviewed with participants in the discussion.

This position statement is not a proposal to attract resources from outside the family network. It is a proposal to stimulate the discussion that will build agreements and lead to resource planning within the family network. The position statement assumes that readers are familiar with support circles and family groups, and the variety of differences among circles and family groups, from their own involvement.

Current realities

A growing number of families in the Durham Region live out an important truth. The quality of family life, and the quality of life for a family member with a disability, improves when a family dares to develop support for its dreams of a positive future. Families[2] live out this truth when they move from isolation to creating and sustaining relationships that help them find and hold their dreams of a full life and to assist them in realizing those dreams.

Circle

Family

Family Group

   Two social forms, the support circle and the family group, now serve these families as holders for their dreams.[3] Though not every family engages both kinds of relationships, circles and family groups complement each other. Circles include and extend the family, offering focused attention on the steps to a desirable future for a particular person. Family groups offer a variety of ways for families to act together on common issues. Both circles and family groups take and hold their form when members act consistent with these common principles.

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[2] While parents are the most commonly involved family members, several participants in the design group make a powerful case for assuring that circles and family groups expect, invite, and encourage participation by brothers and sisters and extended family members. Accordingly, as used in this position statement, "family" includes them.

[3] The diagrams make things look far more uniform than they are in fact. Each circle and each family group has its own size, shape, and agenda arising from its unique history.

- People with disabilities are valuable in themselves, hold the same rights as any other person, and have a responsibility to be present and to contribute to community life, both for their own sake and for the sake of their community. Each person's contribution can be discovered and supported only by respectful, discerning listening for the unique gifts and capacities revealed when people express their dreams in actions, images, and words.

- People with disabilities and their families face powerful cultural and political forces that devalue them and thereby undermine their membership in their communities and their authority to shape their own lives. Existing policies and available services embody contradictions between positive aspirations and devaluing social pressures that typically limit the extent of their contribution and choice. Therefore it is vital that families and people with disabilities…

  …move out of isolation and join concerned others in creating and renewing mutually supportive relationships that will sustain them together through the ups and downs of their lives

  …commit themselves to one another in a sustained struggle to create meaningful lives in the face of powerful, if often masked, forces of social devaluation

  …cultivate a willingness to learn by daring to hold the same kinds of high expectations for people with disabilities that they hold for people who are not disabled; by exploring alternative ways to assist people to uncover and realize their dreams by contributing to community life; and by challenging and examining their own values and understanding in light of the fact that people with disabilities and family members are almost as vulnerable to holding socially devaluing beliefs as anyone else

  …encourage and help one another to invent and implement ways to organize and direct the provision of exactly the assistance a particular person and family need to participate in and contribute to community life

- People with disabilities and their families grow stronger when they meet the challenges of human interdependency. These challenges include…

  …actively confronting the forces of shame and isolation that discourage them by actively reaching out to and joining in with other families, other people with disabilities, and (most difficult) allies from their community

  …avoiding competition with other families or people with disabilities by searching for common ground and opportunities for shared action
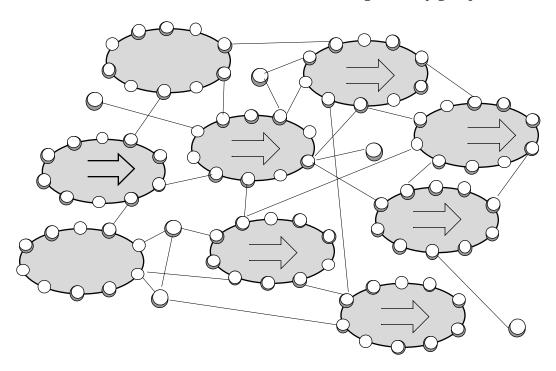
… avoiding the traps set by two common beliefs about the relationship between people with disabilities and their families; namely 1) the belief that people with disabilities should be separated from their families because their interests and their families' interests necessarily conflict, which isolates people from their families and puts them under the control of service providers, and 2) that the interests of people with disabilities coincide with the interests of other family members in such a way that family members can speak for the person with a disability without carefully listening based on an appreciation of the person's distinct identity, which fuses people into their families

- People with disabilities and their families will increase their trust in their own ability to understand and take action to improve their situation when they maintain relationships with others who strive to figure out and take steps toward their own positive futures. Over time, people with disabilities and their families will make the best possible decisions in the context of strong connections to other people who…

  …build trust with them by sharing their lives and their resources in difficult times

  …exchange life stories and share the search for dreams and the means to realize them

  …receive their gifts and assistance and take strength from their example

  …hold hope for building a better future by sustaining a process of focused listening and questioning to discover and take the next positive steps

  …avoid the trap of trusting structures that cannot deliver;[4] such structures can be known by their seductive claims to fix disability, decisively and finally defeat injustice, offer families what they want without their sustained personal investment, or assume complete responsibility for a person with a disability

Circles and family groups benefit from skilled facilitation from someone who can focus her or his attention on the circle or family group's ability to hold the dreams of its members. "Facilitator" is not a term for an answer provider, a personal assistant, a social secretary, or an errand person. It describes someone who assists members to attend to the health and wellbeing of the circle or family group on which they rely. The gift of facilitation flowers in people who trust that people with disabilities and their families will develop the solutions they need when they have a substantial connection to other

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[4] People with disabilities and their families are not immune to the desire to "fix" things for others. Indulging this desire may have its satisfactions and may offer others real though short-term benefits, but acting as the source of other's solutions undermines the context of mutual support.

people and families and who trust their own ability to assist people to find meaning and direction through deep listening. The record in the Durham Region warrants this trust: circles and family groups have the capacity to offer deeply meaningful mutual support, seek and make sense of complex information, win needed resources, and develop suitable structures to provide the assistance and opportunities they need. The record also reveals many families who can't see circles and family groups as the way to the services they want for their family members.

Currently there are a number of family groups, mostly in the southwest of the Durham region. Most people count nine family groups in different stages of formation. There are also families who have convened circles and do not belong to family groups.

Significant changes

Some changes that shape the development of the family network develop from the continuing existence of circles and family groups, others result from Government initiated shifts in the system.

Internal developments

Years of careful work by many families and their allies generate changes that call for development.

• The numbers of families with expectations of investing in developing personalized supports for their members with disabilities grows slowly but steadily as…

…more people from families who have worked for better education and who have high expectations graduate from school

…more families of adults with disabilities realize that the service system will not simply be there to offer satisfactory supports

- Family members who have developed and directed support systems grow or unable to do the day-to-day work of recruiting and supervising assistants.

- More and more people gather the strength –in part because of their participation in circles and family groups– to confront their mortality and search for real answers to the question of "Who will carry on when I no longer can?" While this is preeminently a question for parents, it is also a real issue for key leaders in the organizations that have supported the development of the network.

- Some circles and family groups have stood the tests of time; others have faded. Some circles and family groups have created many new possibilities, others seem to stall. There is much to learn by discovering more about what makes a difference.

- Both the importance of facilitation and the terms of the art of facilitation become more clear, increasing the demand for facilitator time with circles and families and in mentoring new facilitators.

Shifts in the system

While the service system, especially services currently funded though the Ministry of Community Services, can't fully answer the needs of people with disabilities and their families, the Ministry can provide funds to pay for personalized supports and it can pose barriers to people and their families organizing the supports and services that they need. Through the life of the current Government of Ontario, the developmental services system has been in confusion as plans for major changes are announced, resisted, and revised and as big changes have hit other important systems, such as education, housing, income support, local government, and health. While many uncertainties put the situation beyond anyone's ability to fully grasp, it is possible to point to several changes of importance to the future of people with disabilities and their families and the future of circles and family groups.

- Individual budgets, for many years an instrument of family and individual choice and an important basis for family group organizing, have become the centerpiece of the system's efforts to control, equalize, and possibly to reduce, expenditures on everyone in the system. This reverses the power in the relationship between people and the system: instead of being a way to gain some control by fighting for and directing an

amount of money tailored to a person's own account of need, individual budgets become the justification for external assessments of levels of need and the instruments for telling people how much can be spent and on what.
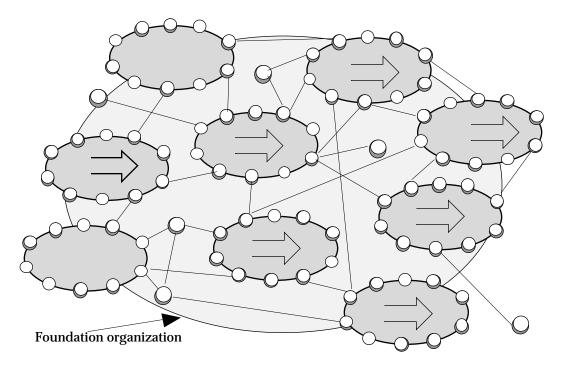
- The idea of people with disabilities relying on "natural family and community supports" has come into currency among system managers as the basis for a policy of limiting government expenditures on services that might substitute for these supports. This not only twists the value of mutual support to justify reduced funding, it also ignores the fact that many people already rely very substantially on assistance from families whose capacity to carry on will be eroded by the reduction of supports and alternatives. The Government's appropriation of the important notion of calling on family and community members makes it hard to bring criticism of the limits of services into perspective: if the powerful stay alert for rationales to cut overall expenditure on people with disabilities, how can people comment responsibly on the misdirection and ineffectiveness of current services?

- The system wants to define all that it funds as its own instruments, dividing its world into separate categories: "clients", "coordinators", and "providers". Many ACL's seem comfortable with assignment to the "service provider" category. However, the organizations that have provided the greatest support to the family network –the Durham Family Network and APW ACL– don't fit this way of dividing the world very well. For instance, APW ACL sees service provision as only one aspect of its work. It has also assumed responsibility for community development through engaging and supporting families to form circles and family groups and to develop and implement a number of personalized support systems. In these efforts, bureaucratically neat separations between "client", "coordinator", and "provider" have little meaning. The effects over time of the system exclusively defining APW ACL in terms of the fraction of its work that involves usual sorts of service provision are hard to predict.

- As part of its effort to rationalize the system, the Government will assign "Access Centres" responsibility for assessment, life-planning, support facilitation, and referral to service providers to carry out plans. There are at least three implications for the development of circles and family groups:

  – Organizations defined as service providers may lose their capacity to form circles and family groups including people who are not already their assigned "clients" on the grounds that this would usurp the function of the Access Centre and confer an unfair advantage over other providers, who have a right to compete for clients

- The Access Center could refer families to a family group with the expectation that they will receive services –or support that reduces their need for services– from the family group. If this were to happen it would violate the most basic principle for generating mutual support; that is, that people choose to be and work together.
- Since funding for the Access Centre will come from existing budgets, funding the Access Centre could reduce the time available to form and facilitate circles and family groups.

Understandably, key people in the family network feel some discouragement at having to deal month after month with uncertainty about just how badly shifts in the system will effect the lives of people with disabilities and their families. And, even if there were no systems changes to contend with, simply continuing to learn how circles and family groups form and sustain themselves in ways that make them fully relevant to the lives of the people who rely on them could challenge confidence in the ability of people with disabilities and their families to shape their own destinies. However, despite discouragement and important questions, there is good reason to believe in capacity of people active in the family network to continue to invent good solutions to the issues and problems they face.

The need for a third kind of organizing

Support circles and family groups have developed to the point that people with disabilities and their families will benefit from another form of organizing.

Foundation organization

Role

As the diagram suggests, this kind of organizing provides a kind of a foundation to the network of families and the support circles and family groups they create.[5] This foundation organization's job is not to steer and not to sponsor but to serve. It does not steer. Each family holds primary responsibility for defining its direction and making and honoring agreements with others. Each circle holds responsibility for the way its members support one another as they help a person and family discover and move toward a more positive future. It does not sponsor. Each family group holds responsibility for discovering what its members need from one another and what they are ready to do together. With these responsibilities go the requirement to develop and locate necessary resources for whatever sort of structures people decide they need, whether that involves hiring and scheduling part-time personal assistants or governing a cooperative that provides assistance to its members.

Functions

This foundation organization serves the network of families, family groups, and circles in at least five ways.

- It assures continuing attention to the health of the whole group of groups and circles, bringing interested people together to puzzle over how to strengthen family groups or circles, how to weave people and circles and groups together in more effective and satisfying ways, and how to encourage groups to face new challenges or deal better with conflicts. Its mandate to discuss and promote reflection on the health and well being of the groups that create it comes from people's recognition that they are part of a whole network that needs tending. It is not the circle police or the family group auditor, ruling circles or family groups in or out of existence. It offers forums for involved people to reflect on what will make the circles and family groups they rely on stronger.

- From time to time it convenes people across circles and family groups to give them the chance to form a shared picture of events and trends that might effect the quality of their lives together. It is not an advocacy effort defining and pursuing a position,

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[5] It is hard to know what to call this. Eric Trist defined something like it when he named the "referent organization." See (1983) Referent organizations and the development of inter-organizational domains. *Human Relations 36*, 3:269-284. My choice "foundation organization" is only to hold the place until someone comes up with a better name.

many effective advocacy groups already exist. It is a way to strengthen and sustain people in the advocacy efforts they choose to undertake by providing opportunities to make sense of what it happening in the community and system environments that affect them.

- It assumes responsibility for supporting the development of facilitators.
- It develops ways to assist concerned people from other places to learn about the work of forming and sustaining family groups, circles, and personalized supports.
- It supports the emergence of new family groups in a way that does not confuse the system's distinction between coordination and service provision or entangle people and their families in client roles as a condition of participation.

Resources

The time to do the foundation organization's work would come from:

- People's gifts of time
- Contributions to this foundation work that legitimately fit people's job roles
- Work carried out as part of grant funded projects designed and governed on a project-by-project basis; as there are already effective ways to hold grant funds, the foundation organization itself would not be the applicant for or administrator of grants; it would provide the forum for defining the content of grant projects and supporting the particular groups that steer their implementation

Limits

The design group acknowledges that there are people with disabilities who are isolated from their families or who belong to families with no real interest in forming circles or participating in family groups. The creation of this foundation organization will have no effect on this limitation in the ways people with disabilities are currently supported.

As envisioned, the foundation organization would not act as an employer or business agent for families, circles, family groups, or facilitators. for the network, and circles and family groups have invented a number of ways to effectively channel and manage service money. Therefore it would not need a legal identity or a bank account of its own.

This last limit was the occasion for a discussion that helped to clarify the work of the foundation organization. It will be worth revisiting this question as work proceeds, so the discussion is summarized here.

<u>Point in favor of the foundation group acting as an employer of staff</u>

- It will meet the real and immediate needs of some family members who feel unable to manage supports on behalf of their family member and unwilling to accept the inflexibility that comes with getting services from existing service providers.

<u>Points against the foundation group acting as an employer of staff</u>

- The role of the family group and the circle is to support families as they figure out what is needed, to support the family as they exercise direction, or to support the development of alternative ways to organizing and delivering assistance. This role stops short of actually doing service management.

- It would blur the identity of circles and family groups as families conclude that joining a family group is a way to transfer concern to an organization.

- Doing this simply because someone needs it would be falling under the influence of "the lure of crisis": short term need would be met at the cost of developing and strengthening the relationships that people and families need to sustain them for the long haul. It risks recapitulating the history of ACL's by turning the network of families, circles and family groups into another service provider.

- It risks confusion of the local movement with service provision and exposes circles and family groups to more intrusion from system planners and regulators because it casts them as service providers.

- Viable alternatives exist and their further and continuing development could be stunted by creating an umbrella provider alternative.

- It should not be accepted as a given that existing service providers are unable to deal with service design and labor relations well enough to offer acceptably individualized services.

<u>Alternatives</u>

- Widen the circle.

- Use the challenge to mobilize the family support group.

- Follow and adapt existing approaches to creating a service management form (e.g. Deohaeko).

- Pool funds with some other families and hire or contract for coordinator time.

- Use an employment service.

- Negotiate with an existing service provider for acceptable arrangements.

Concluding summary

It is time for the families in the Durham Region to create a new form of organization to serve the efforts of their family groups and circles of support. This is not just a new organization, but an unusual type of organization. It is an organization created by the people in the network of families and allies who recognize the importance of conscious refection and action to improve the health and the work of the whole group of circles and family groups that they have created.

This new organization will take shape as people in the network accept responsibility for gathering, reflecting on the needs of the whole network of circles and family groups, and enlisting others to join them in taking action to make the whole network more robust and more responsive to the moral demand that people with disabilities participate in and contribute to community life.