

Tell Me a Story of Deep Delight

An Account of the Work of a Network of Families in the Durham Region*

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* This is an outsider's view, invited as a contribution to the Durham Family Network's Community Innovations Project, "Best practices in self-directed and individualized approaches to supporting person's with developmental disabilities". It is based on a series of group and individual discussions, held between 20-24 February 1996, and represents my reflections on involved people's answers to the question, "What have families in the Durham Region and their allies learned about working for positive change?" The openness and thoughtfulness of the people who shared in these conversations brought some of the mysteries of their common work into view, and the hospitality of the members of the Rougemont Cooperative provided a comfortable base for my inquiries. Preparation of this paper was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B30072) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

Stories of deep delight

Tell me a story.

*In this century, and moment, of mania,
Tell me a story.*

Make it a story of great distances, and starlight.

*The name of the story will be Time,
But you must not pronounce it's name.*

Tell me a story of deep delight.

– Robert Penn Warren¹

Families in the Durham Region whose members include a person with a developmental disability –like families with disabled members throughout North America– face many socially imposed barriers to living so they can recount stories that evoke deep delight. Despite two generations of progress in enunciating the human and civil rights of people with disabilities, the storylines most commonly laid down in our society still dictate shallow, pathetic stories of disability as a chronic tragedy that...

...raises questions about parental suitability (now days usually unspeakable, though still potent)

...calls for brave acceptance of separation and isolation and low achievement and second class status

...looks for hope in benevolent control by professionals who, if they cannot be miracle workers, will at least be predictable, patient and protective.

Throughout North America – as throughout the Durham Region– families, and increasing numbers of people with developmental disabilities themselves, have left behind these narrow and enfeebling storylines in search of ways to live out and recollect their own personal stories. Such stories include disability as one crucial element of a person's identity, an element that is sometimes a help and sometimes a hindrance but never an excuse for passively accepting devaluing treatment. And so, more and more people with

¹ from "Audobon: A vision"

disabilities and their relatives can respond in diverse ways to the invitation, “Tell me a story of deep delight.” Their responses celebrate discoveries of gifts and talents and the contributions and creations that flow from expressing them; they recall hard lessons learned, surprises, angry and funny moments, losses mourned, everyday victories attained, and ordinary pleasures shared; they explain the history and honor the founding and growth of local resources, saying who was first, and what it took, and how things really were.

These are an interesting sort of story. Some of the story tellers have very little spoken or written language; they tell themselves almost entirely in the movements of their living. They mostly travel great social distances from passivity and isolation to engagement and participation rather than great geographic distances. Their starlight shines from ideals of a more just and welcoming community. Like most people, they often seem reluctant to openly name the spirit that animates their stories.

This account offers one description of how families and their allies support one another to make important changes in their own lives and in the communities of the Durham Region. It complements various descriptions that people have made of their own work and the many stories that engaged families can tell about their own creations and the ways that others support them. I will not repeat information contained in available documents or presume to re-tell any of the family stories I was privileged to hear. Because this is my reflection on engaged people’s reflection on the social change they make, it is necessarily abstract, a bit like those essays that analyze the sociology or psychology of humor: interesting possibly, useful maybe, but not themselves very funny. While the nature of the learning makes it impossible to write a recipe for reproducing what they have done, this account may be helpful to people who, having been inspired by the stories families in the Durham Region tell, wonder how to make a bridge to their own situation.

Looking in the right places

Connections are made slowly, sometimes they grow underground.

*You cannot tell always by looking what is happening.
More than half a tree is spread out in the soil under your feet....*

–Marge Piercy²

Families in the Durham Region and their allies have created powerful ways to support one another in moving outside conventional storylines in order to shape their own lives and tell their own stories. Now, some of them have taken on the job of sharing what they have learned with other interested people. There is an economic way to understand this task that says roughly this: innovators invent something whose worth is validated by the marketplace or by scientific assessment, then in return for a licensing fee or as a condition of a grant they share their procedures with others, who improve their productivity by replicating what the innovators did without paying the costs the innovators have paid, thus multiplying the benefits of the innovation while reducing its cost. This powerful idea (which may work for some kinds of things) drives the expectation that if people in the Durham region have had good results they should be able to tell others how to reproduce those results. This expectation makes others impatient to hear the “how to’s” in a form rather like a recipe –even though the demand will be prefaced with the disclaimer, “I know there are no recipes, but... [tell me the recipe anyway]”.

I think clear patterns are emerging among a growing number of families in the Durham region, patterns of relationship and activity that substantially increase the odds that something good will happen for people with developmental disabilities. I think some of the ways to stimulate those patterns of relationship can be described well enough to encourage others to get on with the hard work of cultivating similar patterns among the people who live around them. I also think that the next people who choose to travel a

² from “The seven of pentacles.”

similar path will need to pay most of the same costs that people in the Durham Region have paid, in time and uncertainty and struggle.

Understanding these patterns means looking past at least three other matters that may better feed the hunger for “how to’s”: how families in the Durham Region get and use government funds; how the Durham Family Network functions as an organization; and the particular ways that individual families have grown stronger and better able to form and pursue important goals. These stories will go untold here, not because they are unimportant, but because I want to think of them as clues to the patterns of relationship I want to sketch into awareness.

Someone impressed by the visible expressions of the network –such as the imaginative variety of ways families use individualized funding to customize assistance, or the emergence of the Rougemont Co-op– will usefully inquire about how people got information and made use of government programs and how they organize and schedule personal assistance systems. But this is only part of the story. Acquiring and making creative use of individualized funding for supports means working through a complex maze of procedures apparently designed to discourage families from even thinking about the attempt. Organizing, financing, building, and animating a housing co-operative calls for far more creative energy than even that required to jump numerous bureaucratic hurdles. What else needs study is the ways people sustain one another, over time, to conceive and carry out projects, or wrest individualized funding from a resistant bureaucracy, or keep on with the day to day work of expanding their opportunities. Without an appreciation of this system of sustenance, those who see what families in the Durham Region have done might excuse themselves from the slow hard work of relationship building by dismissing families in the Durham Region as somehow lucky in their dealings with government or somehow fundamentally different from the apathetic, resistant bunch of parents that they must live with where they are.

The organization called the Durham Family Network is one expression of the shared creativity of Durham Region families and one support to its development, but, in any account of the work of change itself, the emphasis belongs on the richly intertwined web of relationships it serves and not on the organization itself. To minimize confusion, I will spell out its whole name, the Durham Family Network, when I refer to the organization. Otherwise, I use the word “network” as many involved people there do: to refer to the web of overlapping person-to-person, family-to-family, and group-to-group relationships that form the common root system for many different projects and activities. What is above ground is exciting and how it works is interesting, but what is vital to its growth is the tangle of connections beneath.

A visitor can't help but be impressed by the number of committed family members (mostly parents and, more often than not, mothers) who make important things happen in the Durham Region. There are many talented, tenacious, and courageous individual parents, and they do have access to a variety of sources of good information and skill training. But, while considering their individual abilities gets close to the heart of the matter, it doesn't seem to fully describe the local movement. Other communities have people of equal talent and commitment. Their training and information links are of very good quality, but don't seem to communicate secret knowledge hidden from people in other areas (or if they do have such secrets, they managed to keep them in conversations with me). As important as individual stories are, the other thing to look for is the patterns of relationship and action that mobilize and sustain talented and committed people.

Four flows of activity seem to form the patterns of support for change in the Durham Region:

- People reaching out to form multiple, overlapping, expanding and deepening relationships.

- People conversing about what they want most and what stands in the way of working for it and what helps to move on to the next step and thereby shaping a common way to understand the dangers and the possibilities in the situation that families face.
- People attracting and organizing the resources they need
- People facilitating the development of the network in ways that express a deep commitment to emergence³

Multiple ways to connect

*Keep tangling and interweaving and taking
more in,
a thicket and bramble wilderness to the outside
but to us
interconnected with rabbit runs and burrows and
lairs.*

– Marge Piercy⁴

There are many ways for families and their allies to connect with and be part of the network.

- Some families get information by reading a publication, attending a workshop, or raising a question on the phone
- Some families belong to organizations that get or share a variety of support services
- Some families benefit from a relationship with a Resource Parents, others from the support and training available to them as Resource Parents
- Some families get connected directly to other families for mutual support
- Some families get focused help from more experienced parents when their situations are especially difficult
- Some families link the Durham Region with provincial initiatives on behalf of families

³ This is a key idea, and I know it seems mysteriously undefined at this point, but I think it will be easier to point to after a discussion of the other three flows of activity.

⁴ from “The seven of pentacles.”

- Some families have created support circles that link their allies among service workers and other community members into the network
- Some families belong to a family group.
- Some families have made solemn long term commitments to one another involving such matters as guardianship and supported decision making for family members with developmental disabilities.
- Some families have joined other families in creating new structures and organizations like Deohaeko.

An ethic of hospitality and mutual support animates this array of ways to connect. If you are a parent, and you choose to be involved, you are welcome. Other parents will do their best to make room for you, listen to you, share what they know with you, and help you out as much as they can. If you seem awkward or difficult, or if your views don't match those of others who have been involved longer, they will struggle not to judge you, and they will not reject you, though they may question you in an effort to help you consider new possibilities. You are honored and included simply because you are the parent of a person with a disability who seeks to make things better for your family.

This network has many different kinds of boundaries, allowing family members many choices about how close to get and to whom. Many boundaries in the network are fluid. Some people dip in at the edge, exchanging a small bit of their personal story for some information and advice. Others come together for a particular campaign or project. Other boundaries are more solid. Some clusters of people in the network are very closely tied indeed: their sons and daughters, and some of them, share living arrangements and co-operate in organizing and managing needed supports. Some boundaries, such as the co-ops and contracts people have made exist in law and define membership formally. Some boundaries, such as those around the family groups, are emotional, strengthened by sharing stories and experiences and support through time.

Three issues make this neat account of boundaries fuzzy and interesting. It is important to note that the network doesn't have a membership committee or by-laws or policies about who is in and who is out. If it did it would cease to be a network. But these questions occurred to me as a visitor and my sense of the answers local people gave may add something to an understanding of the way they understand their web of connections.

- What about family members whose goals seem to run counter to those of most network members, for example, a parent who publicly advocates expanding institutions? The clarity of the public positions taken by many network members as individuals and as part of organizations and campaigns may make it unlikely that such a person would seek to join in the first place. But my guess is that if a person with such a position approached, she would be welcomed as a parent seeking to discover and act on what is best for her son or daughter, encouraged to share her story and dreams and to listen carefully to the stories and dreams of others, and invited to ask for help and offer someone else help, or join in some common project. The willingness to share, to search, and to give and receive help are the basis for belonging. However, if the person's goal was to enlist public, political support she would discover an interesting feature of networks and the kinds of support groups that form and re-form around them: initiatives form around voluntary choices. Unlike formally constituted associations (like Associations for Community Living) networks don't take positions; they don't vote resolutions up or down to define where they stand. The people linked through them, and the groups and organizations they create, may take positions and work hard for them, but the network does not exist in such a way that it can be directed or hijacked or subverted.
- What about people with developmental disabilities themselves, especially adults? If parents are the experts, how do the distinct dreams and voices of their son's and daughters emerge? In one sense this is a non-issue: part of loving someone is wishing for them to grow in autonomy and a number of parents say that one of the happiest surprises in the work they have undertaken on their child's behalf is the growing

expression of their son's or daughter's distinct identity, often through conflict with parental views and wishes. But this is an important practical struggle even, or perhaps especially, if the person has a substantial disability and limited communication.

Connections to the network will raise questions, perhaps through hearing another parent's question reverberate within, and connection to people in the network will offer a variety of supports to find the next steps.

- What about committed people who are not parents or brothers or sisters of a person with a disability? Allies –some of whom are community members and some of whom are paid service workers– are valued members of some people's support circles. People who are not family members play a key role in developing family groups and assisting family members to deal with difficult situations. A few non-family members are active and influential in most network activities, even though they are invisible in the official story about the network. These are the qualities that seem to matter in an ally:
 - Profound respect for the fact that people with disabilities rely on their families for an irreplaceable contribution
 - Ability to listen long and hard to multiple family views before deciding whether to offer opinions or advice about what to do
 - Willingness to put their knowledge and skill at the service of families, and to join in practical action
 - Following through and being present out of choice, over time
 - Not being defensive about the negative behavior of professional or bureaucratic systems
 - Not quibbling about whether occasional “family member's only” boundary statements leave you out.

As the number of people who exchange some time and energy through the network increases, the network grows wider. As the number of people who are linked to one

another in multiple ways increases, the network grows more dense. The wider and denser the network, the greater the potential for action.

A way to understand

*watching the spider
rebuild—"patiently", they say,
but I recognize in her
impatience—my own—
the passion to make and make again
where such unmaking reigns
the refusal to be a victim...
My heart is moved by all I cannot save
so much has been destroyed
I have to cast my lot with those
who age after age, perversely,
with no extraordinary power,
reconstitute the world*

– Adrienne Rich⁵

The network of connections carries many conversations that arise from families' search for better futures. These conversations shape ways to understand the situation that validates families' experience, offers a place to stand outside commonly available storylines about disability and about service agencies, and sets high expectations for action together. The more people share a common understanding the more likely it is that the many different actions that network members take will be aligned at the level of purpose. The longer a person has been part of the network and the more different ways a person is connected to the network, the more a person will share and shape this point of view.

This way to understand has grown up as many different people have, working together on getting things done, talk to each other about...

...their everyday experiences as members of a family with a disabled member

⁵ from "Natural resources"

...their desires and dreams

...their experience in negotiating what their family needs from professionals, schools, service agencies, and government programs

...what comes to them through participation in local, provincial, and national associations

... their learning from continuing involvement with...

...l'Arche, Citizen Advocacy, and other less formal sorts of lifesharing between people with and without disabilities

...training and thinking on Social Role Valorization (SRV)

...the perspective on community building elaborated by John McKnight

...the approach to community organizing taught by the Gamaliel Foundation in Chicago

There are, of course, as many different particular understandings as there are involved people. Some people put more emphasis on sharing life and others emphasize organizing actions to compel government and agencies to deliver necessary resources. Some people are more tolerant of the theoretical nature of SRV than others. Some people like to talk things over, others want to get something done. Some people are more committed to drawing members of the non-disabled community into deeper ties and connections with people with developmental disabilities than others are. But a common way to understand their shared situation continues to emerge among these families and their allies.

This way of understanding grows from heartfelt conviction of the inherent dignity and worth of the person they love, and a deep belief that people with developmental disabilities rely on their families to play an irreplaceable role as experts on what matters most in their lives and as agents of social change. Anything that threatens the person's human rights or constrains family members ability to play their vital role is a target for resistance. Any step that family members take to develop opportunities for people with

developmental disabilities and their families to find their rightful place in community life deserves support.

Some of the themes in this emerging perspective have to do with understanding what those who love a person with a disability must work against ...⁶

- A recognition that many common practices in community life and in the day to day workings of service programs and government agencies devalue the person they love and a belief that such prejudiced treatment ...
 - ... is morally and legally wrong
 - ...is the problem of those who act out of prejudice, not the fault of people with disabilities or their families
 - ...must be confronted in ways that will make a real difference; this means balancing sustained strategies for political and cultural change with reactions that deal with particular incidents in the best way possible at the time
 - ...is deeply entrenched economically, politically, and culturally and so negative forces will often “win”, at least in the short run; this is not an excuse for withdrawal but the reason to be involved
- A belief that parents have an unmatched understanding of a vulnerable person’s situation and a place in their life that cannot be filled by anyone else, and that this place must be claimed and defended because family power...
 - ...threatens professional control and status and bureaucratic notions of efficiency and priority

⁶ I compiled this list of themes from notes on my conversations with people. I have used and combined people’s own words and phrases as much as possible but the list should be read for what it is: my effort to indicate some of the themes for talk and action that move among involved families in the Durham Region.

...exposes the general inability of service agencies and government programs to hear and make reasonable accommodation to differing individual assets, needs and interests because of the extent to which these agencies and programs are compromised by other powerful agendas, agendas which express economic and administrative ideologies or control by managerial and professional guilds or labor unions.

- Common defensive mechanisms deployed by serve agencies and bureaucracies to stifle family power include...

...withholding important information on the grounds that it would be too difficult or too stressful for family members to understand it, or that informing families would compromise an organizational prerogative to keep secrets

...creating a maze of complicated, tiring, and silly procedures for dealing with even the simplest requests for change

...hedging anything that gives people or their families more control of resources with especially tedious and demeaning bureaucratic procedures

...perpetuation of the myth that a person with a disability is broken and will only be fixed through enthusiastic cooperation with the prescriptions of professionals who work in bureaucratic structures; and raising the fear that failure to cooperate will make things worse, through the fault of the noncompliant person or family

...perpetuation (usually subtle) of the myth that having a child with a disability is the shameful result of parental, usually maternal, defect and that the only ways to atone for this shame are enduring silence, compliance, and gratitude for whatever others offer

...locking in the myth of shame by upholding the myth of normality in the form of an impossible standard of conformity with a narrow idea of “appropriate behavior” for both people with disabilities and their parents; accepting unreasonable expectations creates a daily diet of failure and shame

...perpetuation of the myth that meeting reasonable needs for assistance places an unreasonable burden on the public purse and that families of people with developmental disabilities have gotten far more than their fair share of public money for what is really their private responsibility, especially in comparison to other socially disadvantaged groups, and so should expect scarcity, intrusive procedures, and managerial control of their lives in order to satisfy the taxpayer

... pitting parents against one another by encouraging comparisons of what one family gets in the way of resources with what others get, or setting up parents to fight with one another by using the desires of one as an excuse for ignoring the requests of another

...rewarding passivity and going along with bureaucratic processes through various kinds of praise ranging from pats on the head and small considerations in services to prestigious awards and special access to official meetings

- Living day after day with all of this is tiring, discouraging, and dispiriting; it leads many family members to withdraw into passivity, settle for what is offered, swallow their anger and humiliation, pretend that the experts really can raise their children better than they can, and scale down their expectations for a life that makes more sense

Other themes in this emerging perspective reflect an understanding of how those who love a person with a disability make things happen...

- People grow strong on the dreams of those who love and care for them; dreams grow stronger when people overcome their fear and give voice to them in a way that recruits allies and organizes a way to take the next step
- People's gifts, capacities, and contributions make a better base for engaging, assisting and supporting them than their problems, deficiencies and needs do; what's important is to open up individually relevant ways for people to make real contributions; this works for people with disabilities just as well as it works for other community members

- Few, if any, important dreams can animate action unless people get and give support by reaching out and bringing in others; in order to take charge of one's own family life, it's helpful and energizing to become intertwined with the lives of others
- Sometimes anger, especially hidden anger, blocks the ability to dream; for many people anger at unjust and hurtful practices provides great energy to move from passivity to action to get what's needed; so anger is a welcome resource for those who feel it and direct it toward changing unjust conditions
- Sometimes unshed tears block the ability to dream; some people grieve for the hurt done to people with disabilities and their families by rejection, and withdrawal, and segregation and punitive control, and low expectations; great energy can be liberated if people find the courage to share grief and consolation
- Not even love is strong enough to keep a parent from swallowing some of the negative myths that surround people with disabilities; it's important to be open to what one mother calls "clunks" (as in "clunks to the head"): realizations of the ways common prejudices have distorted one's own understanding and stunted one's own dreams
- Discovering limiting belief's in oneself is something to celebrate, not something to be ashamed of; once seen it can be challenged and changed
- The ghost of "normality" that haunts many families can be laid to rest when you find others who will join you in this strategy: "Become 'normal' by accepting that we are not 'normal' and never will be. Recognize that we are just families, not good families, not bad families, just families working for a just and welcoming community"
- It is a mistake to believe that any bureaucratic agency or program can be entrusted with a person's life; people with developmental disabilities need a whole circle of people who are willing to commit themselves to listening, understanding, and working with a person for good experiences
- Being certain of people's rights, being informed about how the system is supposed to work as well as what really moves it, being organized, and being persistent well past

the point of anger are the necessary conditions to win even simple accommodations from the system

- Once won, accommodations are easily lost, more often by erosion than by direct reversal; so continuing vigilance is necessary
- People with developmental disabilities whose families and allies can take control of necessary personal assistance and support arrangements, perhaps by buying services from an agency, have better chances for good experiences than people whose assistance and support are completely controlled by a bureaucratic agency
- It's important to organize politically to fight for policies that offer people and their families the option of meaningful and direct control of the assistance and support they need, this must include the choice of people or their families directly managing the available money
- The best response to defeat is to re-group and figure out how to try another way; people can help each other by granting each other permission to make mistakes and fail and by encouraging one another to pick up the pieces and get back to work
- The key to making change is to adopt an attitude that together we will do whatever it takes to promote people's human right to be a valued participant in community life

This way of understanding is not presented in lectures or used as a catechism. In fact, many of these themes have little impact when considered abstractly. Who could disagree with the idea that you must organize to make change? The hard part is finding a way to remember the idea and turn it into action when stuck in complaining about how one is victimized. These themes grow, and grow influential, as people talk with one another while they work and plan and sort out disagreements and misunderstandings together.⁷

⁷ In the course of one of our discussions, the term "discourse" was borrowed from cultural theory and used to describe the kind of limits on what can be said that reproduces power-over people and limits action. In

As people discover and share their way of understanding their situation they develop a common point of view and a common vocabulary. This particular way of understanding seems to accomplish at least two things for the network.

- It validates what many people have believed were idiosyncratic and often somewhat unacceptable perceptions and feelings and makes these very things the basis for sharing (“I thought I was the only person in the world who experienced this.”)
- It attaches the energy set free by this validation to clear expectations that people will take positive action and help others who are moving along the same broad path.

Access to necessary resources

*Anger and tenderness: my selves.
And now I can believe they breath in me
as angels, not polarities.
Anger and tenderness: the spiders genius
to spin and weave in the same action
from her own body, anywhere—
even from a broken web.*

—Adrienne Rich⁸

Services

The central concerns of many people most deeply involved in the network lie at the outer edges of the formal systems that service people with developmental disabilities. Offering services that respond flexibly to changing needs as defined by families or people with disabilities stretches existing agencies, often beyond their limits. Inclusion with strong parent involvement is a new and unfamiliar, and too often unwelcome, endeavor for schools. Individualized funding that actually places control of required services in the hands of people with disabilities or their families is a small, apparently uncomfortable, marginal investment for governments of all persuasions. Ventures aimed at joining

context, the point is that the network exists to do the work suggested by these themes, work that will confront a discourse of exclusion and professional/bureaucratic control.

⁸ from “Integrity”

different kinds of social concerns and different kinds of funding to build community around diversity are unusual, if appealing.

This position at the edge of business as usual makes the network an important force for change in the way services are delivered. But service agencies in the region vary in their openness to such change across a spectrum from rejecting its possibility to welcoming the stretch, even though it increases variety, uncertainty, and conflict. Agency managers who reject the chance to change often have high motives for doing so: they worry about burdening people with disabilities, parents, and staff with unrealistic expectations; they are concerned about the equity of providing some families with what they want while others go without; they feel an obligation to listen to those families who are satisfied with existing services and would be disturbed by significant changes, even if those changes only involved other families; they believe that people with developmental disabilities already consume too much in the way of public funds.

Some families find that even the most open service agencies can't offer the necessary resource flexibility and a culture that consistently expects and supports the kind of personal involvement that support staff must have if a person is to have their best chance at a desirable future. This has led some families to take charge of their own arrangements, with varying degrees of specific help from existing agencies; others have joined together to create a new support organization; others are delaying major changes –such as a person moving out of the parental home– until better alternatives develop; and at least one family now wants nothing from the system apart from an adequate level of individualized funding and the authority to spend it as they see fit.

For many families, basing services on individualized funding seems like the best alternative. Unfortunately, where families and their allies see opportunity, the government bureaucracy sees danger, and provincial organizations whose members benefit from current arrangements see unwelcome conflict. Network members work in many ways to increase the availability of individualized funding the offers people and their

families genuine control. They support one another to slog through the nearly endless bureaucratic swamp to get funding for their own plans while they work on province wide efforts to influence Ministers and civil servants.

It is a tribute to their resilience that family members can identify some benefits even in the slow and insulting process they have endured to get what they believe is rightfully theirs:

- The need to argue and reargue their case has sharpened and refined some family's plans while it has discouraged many more families from even considering application
- People have made good use of bureaucratic delays to organize things so that funds can be well used when they arrive, though they have paid substantial costs in missed opportunities and discouragement for the delays the process imposes
- Chronic under-investment and widespread denial of what seems to make common sense has provided a good issue to organize around, although there are many other good issues arising from service practice and community life that would probably have more long term impact on social patterns than fighting the bureaucracy will have

On balance, much easier and quicker access to sufficient individualized funding under a person or family's control will be vastly better than the current unjust and inefficient policy. But, in spite of system inertia, families have been able to create an impressive variety of individualized support arrangements. As these arrangements develop, they generate new, practical possibilities for other families to learn from and adapt to their own circumstances.

This signals health in the network. Families have not been trapped in the paradox of trying to create a blueprint for individualized services that would bureaucratically replicate the same individualized arrangements for all. Each time another family wins the individualized funding they need, they increase the variety of ways of providing individualized support.

Support for network building

Cultivating and tending and extending the web of relationships that give the network its potential for action is hard work for gifted people. Each particular connection, each circle, each project, each family group is drawn together by its own energy and has its own capacity for reaching out and taking action. But when families face the difficult tasks of day to day life, and the demands of earning a living, and the tasks of making social change, experience shows that some extra energy focused on building and re-building relationships multiplies whatever energy and capacity for action is already available.

Having this kind of support is not a matter of someone to assign tasks to, but someone to see that the webs of connections necessary to sustain action are woven and then, as they inevitably break, re-woven. This work is about accompanying people as they struggle to find direction and then to enlist companions and take on new tasks; it is not about going on errands for them.

Many people in the network are finding time to act as advisors, guides, and mentors as their own situations reach a point of stability. Most of this work is done outside the cash economy. A few people have enough economic security to give care and attention to making and remaking important links without concern for their income. And other people with an artistic gift for connecting and organizing people can make their greatest contribution if they can make at least part of their living from that work.

Economic support for network building comes in these forms...

- Short term grant support for projects that are designed to build the network while accomplishing the purposes of the grantors
- Budgeted funds for coordination, facilitation, and community building built into the projects and support arrangements generated by network members
- In-kind support from the Ajax-Pickering-Whitby Association for Community Living in the form of staff time –especially senior staff time over the course of years– which has

been dedicated to organizing and facilitating support circles and family groups, assisting in planning and preparing projects and proposals, and supporting learning throughout the network.

- A variety of contract management and other support services from service agencies

Anyone who wants to build up the kind of possibilities for action that now exist in the Durham Region had better be very sober indeed about the sheer amount of time, over years, that goes into building up a network. Because the potential for action grows as smaller efforts touch and energize one another and trust grows over time, the first expressions of a developing network will look very different from number and the kinds of things that will happen as connections grow wider and denser. Some people will decide that it's not worth the wait and move on to the next answer. But it is not wise for someone who plants a tree to impatiently uproot it's first small shoots because they do not seem to offer shade.⁹ It takes time to cultivate a network that starts to generate so many different initiatives that no one seems to be able to hold them all in their head.

Belief in emergence

*We join spokes together in a wheel,
but it is the center hole
that makes the wagon move.*

*We shape clay into a pot,
but is the emptiness inside
that holds whatever we want.*

*We hammer wood for a house,
but it is the inner space
that makes it livable.*

–Tao Te Ching

Family groups frustrate the hunger for “how to’s” more than any other aspect of the network. Some of the most interesting tangible accomplishments of the network are the product of family groups. They seem to be the places where the web of relationships is

⁹ I have stolen this phrase from somewhere, but I can't think where; probably from one of the Vulcans on *Star Trek*.

deepest and densest, and so the places where people feel particularly strong support. The obvious question: “How do I get some family groups working where I live?”

The frustration begins with asking knowledgeable and directly involved network members what they mean when they call something a family group. They answer by pointing out the many differences among them. Each family group has its own identity, its own way of organizing support for its members, its own achievements, and its own history. What they have in common is that they are a groups of families, linked somehow into the network not just as individuals but as a group. In fact, the label is so wide that knowledgeable people don't agree how many family groups there are. (The differences in the count depend on what the enumerator takes as a clear sign that a family group has formed.) This variation doesn't concern the people involved, in fact they see it is a sign that the process they want to facilitate is working. What's bad for a linear logic of classification may be good for making social change.

Probably the biggest stumbling block to understanding how family groups develop is the simplicity of the process. Note that the descriptor is “simple”, not “easy”, or “surefire guaranteed”. It can almost be reduced to a recipe:

- Identify families who are aware of a great need for better support and invite them to gather with each other. Many involved families described themselves as coming to the first meeting out of a sense of desperation, or a sense that there were no real alternatives to turn to, or a sense of deep confusion about what to do to provide for the person they love.
- Make it clear from the first that, as the convenor of the group, your hands are empty: this process not a way to gain access to an existing service or any source of funds. Anything that happens will happen because people in the family group want it to happen and work to make it happen. This message will almost certainly need repeating, and, despite your best efforts to be clear up front, some people who attend will feel let down and angry when they discover that you are telling the truth.

- Respond to questions about “What’s the use in doing this?” by encouraging people to try it because other some family members have found it helpful. If people still have questions, invite them to talk to members of other family groups. Avoid being drawn into doing a sales job.
- Begin the gathering by asking the people who have come to take turns sharing their personal stories. Listen carefully, from a position of deep respect, to whatever people choose to tell one another about their life as a family with a disabled member.
- Do what any member of the group needs to do (none of this will work as a detached technique, it either comes from your heart or it doesn’t come at all)...
 - ...Listen carefully and make sure people know they have been heard
 - ...If there is something you feel personally called to do, offer to do it and then either do it or accept responsibility for failing to follow through
 - ...Clearly identify opportunities for people to offer one another practical help
 - ...Help the group remember to keep the person with a disability in the center of their concerns
- Avoid giving advice. Simply encourage the people who feel a connection to keep meeting again and again for the purpose of discovering more about each other and more about the ways people can support each other.
- Invite people to share their dreams for their families and for the person they love who has a disability. It may help to acknowledge that story telling and dreaming take practice with a group that is committed to listen and support; there is no right or wrong dream or story, only a kind of sharing that helps some people find direction and energy
- Expect that some –maybe many– people will not find what they came for in the group and leave. Some family groups have stabilized with about a third of the people who were involved in the early stages. However it seems impossible to predict who will find

what they are looking for and who will not, so it makes sense to invite anyone who might be searching. Also, some of the strongest members of family groups remember a longish period of struggling to figure out what the contribution of the group would be. People don't need a clear reason for getting and staying involved so much as a sense that something pulls them and keeps them connected to these other people.

- Expect it to take some time for the group to find its identity and direction, perhaps as much as a year or two. Each family group will find its identity and direction in its own way. They will do this through a unique combination of group sharing and providing one another practical help in planning and taking action.
- As the family group wants to explore possibilities for action, it may help to link them to members of other family groups who have experience along the same lines.
- As the occasions arise, invite interested family group members to make other connections with people and activities in the network.
- Encourage people to keep revisiting and retelling their story and their dream. This can be done in times of celebration, or reflection, or reorientation after hurt or disappointment, or defeat.
- Get even smaller than you started as soon as you can. But no matter how small you become, listen big and deep.

If I were making up a Chinese character for this approach to facilitation, the parts of the depiction would translate something like this: "Listen with empty hands and an open heart. Right action will come."

There is a sting in this excursion into recipe writing. To describe how someone who wants to animate a family group behaves is much easier than to do it. The doing throws the person back on what they believe. Acting on the assumption that whatever emerges as people share their stories and dreams offers the best chance for good things to happen for people with disabilities can be a severe test. So can acting on the belief that family members' love does hold vital knowledge and energizes capacity for deeply fitting and

creative action. Resisting the temptation to define prerequisites for being a family teller of stories and dreams will sometimes be difficult, but the facilitators willingness to avoid the familiar role of expert answer-giver encourages the emergence of people's own voices and directions.

Not everyone has the gifts necessary to set a family group on its way, and no one who tries "succeeds" every time. Other people in the network have other gifts (perhaps a gift of impatience to confront injustice and wring some concession from a senseless system); the breadth of the network increases the chances that they will find ways to contribute that match their gifts.

There are some mental blocks to understanding the development of family groups. For example, many of us assume...¹⁰

...that a complex result must be the product of detailed planning and authoritative management; this is at least partly true for some activities, like building a house or scheduling attendant care; but the impulse and energy from family groups that has created new households arose as people explored their dreams and the possibilities for realizing some aspect of their dreams and not from following a blueprint

...that it should be possible to "reverse engineer" change by disassembling a good thing into its historical components and extracting the process for reproducing similar results; but even when the same people facilitate, different family groups follow distinct paths, probably because people with unique combinations of circumstances gather and co-evolve within different environments

...that the effects that emerge when people come together should be predictable from the individual intentions and plans that existed before they encountered one another; but

¹⁰ My writer's block about this aspect of the network was eased by listening to a tape of Margaret Wheatley, *Leadership in a self-organizing world*. Audio taped address to the 1995 International Conference on Servant Leadership. Indianapolis: The Greenleaf Center for Servant Leadership.

telling and retelling stories and dreams to a respectful group allows undreamed of possibilities to take shape between them

...that big and urgent problems call for big and immediate solutions; but the network has elaborated many small steps toward better lives that have shifted the environment for others

Once it is possible to overcome these mental blocks, some possibilities become clear.

Families need containers for their dreams. What is useful about a container is its emptiness, its openness to be filled with what a family really wants. This useful emptiness can be made through the experience of belonging to a web of personal support, especially when that broad web of relationships becomes deep and dense as people gather to listen, to share, to shape a powerful way of understanding, and to act to change their world.