

Known by the Stories We Tell

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There is a certain embarrassment about being a storyteller in these times when stories are considered not quite as satisfying as statements and statements not quite as satisfying as statistics, but in the long run, a people is known, not by its statements or its statistics, but by the stories it tells.

–Flannery O'Connor

Why now?

There are at least three good reasons for the people who create and count on DFRS to invest time in considering the question that brought us together on 24 January: **Who are we to each other and to families today?** All are related to major changes in the developmental disabilities service system as the Ministry continues the multi-year process of implementing the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*.

First. Families experience new uncertainties as a result of changes to the eligibility determination, resource allocation, and direct payments management processes. New acronyms –DSO and SIS– indicate a shift in the people, place and procedures where important decisions affecting a family's paid supports will be made. Legislative concern

¹ These my reflections on a discussion on 24 January 2012 that involved the Board, staff and allies of the Durham Association for Family Respite Services (DFRS). The purpose of the day was to explore better ways to articulate what is distinctive about DFRS, given the concerns raised for families and for DFRS by the transformation process being implemented by the Ministry of Community and Social Services (the Ministry). This report is a step along the way to better self-understanding among DFRS' people, not a finished product. These reflections do not give equal weight to all areas of the discussion. I have briefly summarized much of the discussion, which understandably focused on the uncertainties imposed by the restructuring of the system and the actual and potential negative consequences that participants in the discussion associate with system changes, I have focused on what I heard people say that might add to DFRS ways of expressing its self-understanding. At Peter Dill's invitation, I have included ideas gained in conversations outside the meeting with people associated with DFRS and discussions at a workshop on 23 January that included people from several of DFRS organizational allies. These reflections were drafted on 29 January 2012.

for equity and fairness (understood as treating all alike and objectifying allocation decisions) have not yet translated into a concern for adequacy of funding, so a growing number of families continue to wait for funding or find ways to stretch inadequate funding over increasing requirements for paid assistance. These demands on families' adaptive capacity call for a check on DFRS understanding of its identity and contribution to family well being.

Second. As the agent of a bureaucratic service delivery system with a particular charge to deliver Respite Services, DFRS faces uncertainties about the effects of the Ministry's changing conditions for funding. The Ministry's understanding of quality includes a focus on holding agencies to specific service definitions and increasingly detailed standards. This could threaten DFRS unique and flexible understanding of the meaning of respite, pushing a concern for overall family thriving into the box of delivering out-of-home beds intended to temporarily relieve the strain of raising a child with a disability. The Ministry's understanding of efficiency may include a significant reduction in the number of Transfer Payment Agencies, which could affect DFRS ability to assist families with managing funds. This sort of efficiency also drives a policy of amalgamation of agencies which, at its most extreme, could result in the re-assignment of DFRS Ministry funding to another single regional service agency. Negotiating the flexibility and resources necessary to do its work requires DFRS to be both strong and articulate in what it stands for.

Third. DFRS is one of a small number of organizations in Ontario with a deep understanding of what it takes for families to contribute in a powerful and creative way to building good lives and social inclusion² by melding their own capacities, community resources, and service funds to support people in valued social roles. This knowledge is of great potential value to many more families and should make a difference to policy makers. Finding effective ways to share this knowledge has been a long-standing issue for DFRS. It has been especially frustrating as families who have a generation's depth of learning have dutifully attended consultations and hearings and had their words taken down appreciatively, supposedly to guide Ministry Policy as the system is "transformed".

² Oddly, at least to an outsider's eyes, beyond its title reference to social inclusion the act is devoid of statements of purpose or principle. It simply grants the Minister a series of authorities to re-structure the developmental services system: it is all and only about the plumbing of services. Concurrent Ministry announcements of the act say that it promises people greater control of their own lives, largely through what appears to be a goal setting process called "person-directed planning" which will be defined and controlled by the Ministry but say nothing much else about purpose and values.

The results so far have been worse than being ignored. One person says, *I have accepted invitations to tell our story to policy people. They have written down my words about what we have learned from more than 20 years investment of energy, passion, and our own resources . But our contribution is not acknowledged. What we have learned is not valued. What comes back to us in their policies is as if we were never there. It's insulting.* Another summarizes, *They take our words and give us back what we do not mean.* Struggling to find more and better ways to communicate what DFRS families know is a continuing opportunity to offer service to other families and fulfill the duties of citizenship by trying to inform policy.³

Telling our stories in a strange land

Attending to this frustrating and recurrent phenomenon of being incompletely understood may produce greater understanding of what is distinctive about DFRS' identity. Good things are happening for families associated with DFRS. Good things that seem to exemplify stated policy directions and the desires of families outside DFRS. But, though many have been told the stories, relatively few families and their organizations outside DFRS orbit have chosen to follow the paths DFRS families have blazed. And Ministry policies informed in part by consultation with DFRS families could limit DFRS capacity to do its work.⁴

The problem is not lack of clear expression. DFRS mission, beliefs, and principles are well expressed. There is clear commitment to supporting whole families to care for one another, maintain control of their family life by making good decisions about the role and provision of respectful, responsive and capable paid assistance in their family, and promote development and valued social roles that make the most of community life.

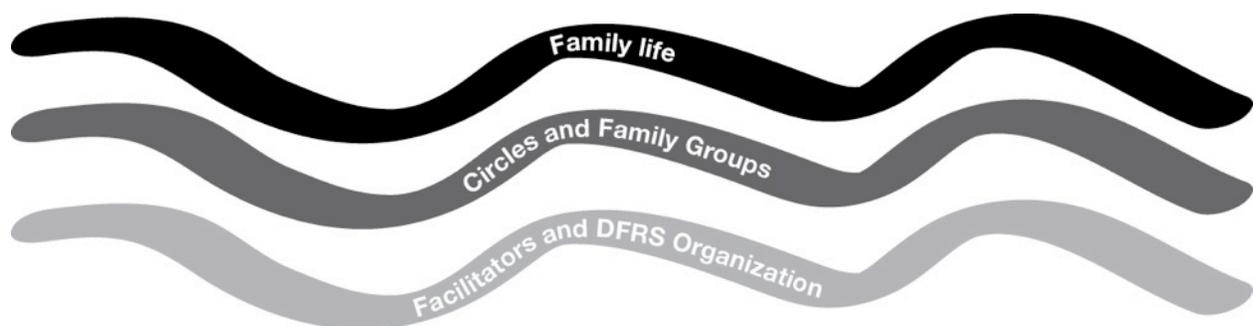
The problem is not that the words that express beliefs and principles are hollow. Many years of action and reflection have refined these words, developed the practices necessary for a growing number of families to live them, and incrementally made room

³ The low probability that the Ministry will or even can take our words and give us back what we do mean makes continuing effort to inform the Ministry a gesture justified by the principle of "act validity". However, limited chance of success does not absolve the duty to try and trying may be part of getting a hearing as DFRS negotiates for the space needed to continue its work.

⁴ There was considerable discussion of strategies for telling DFRS' story in more influential ways and Board member interest in considering how this might be done. This paper focuses on what some of the messages about DFRS' distinctive identity might be rather than how those messages can be influentially transmitted.

in the Ministry governed system for DFRS to finance its work. Out of this shared action have come many stories: stories of what families and family groups have accomplished and the limits they have met; stories of how circles and family groups can be called and facilitated; stories of what community people and settings can contribute; stories of ways to make the best of continuing shortfalls in funding for assistance; stories of what it takes to recruit and develop good assistants.

The problem of being understood may lie partly in the difference between the stories associated with DFRS and the dominant narratives in the strange lands of typical Ministry services. DFRS supports families, circles, and family groups to generate action that can be captured in stories about three distinct but interdependent streams of action. There are stories about how individual families are living. There are stories about how circles and family groups come together and generate support and opportunities for engaged families. There are stories about the ways that facilitators and DFRS as an organization contribute.



From the point of view of the people who live them, all of these stories are simply about everyday life. They may differ somewhat from the stories their age peers who do not live with disability tell about their everyday lives in that more of family life is shaped by concerns and work related to assuring the best life possible for the family member with a disability. They may differ somewhat from the stories many other families with similarly labelled people tell about their everyday lives in that more of their lives reflect their continuing investment in the intentional creation of and participation in circles and family groups and their commitment to seek and support valued social roles for their family members.

From the point of view of the most culturally common story lines about life with disability, stories about family life told by those associated with DFRS seem consonant when they

are stories of complaint about insufficient and insecure funding, systems that are hard to understand and difficult to navigate, disrespectful treatment by professionals and system gatekeepers, and the difficulties of getting competent and flexible individualized assistance. Far beyond complaint though, DFRS family stories can touch people's heart's desires when they recount the ways that people have stuck together and cared for one another year after year in changing circumstances and when they describe the quality of life that many people experience⁵

It is when the stories begin to incorporate the other two streams that their strangeness is amplified. DFRS itself has developed ways to invite people into living a life that includes investment in circles and family groups and a form of support that is not measured in scheduled turns at days in a respite bed. It involves welcoming parents and beginning with the question most on their minds –for example, *We need regular breaks from taking care of our daughter.* or *My son has outgrown his pediatrician, who will be his doctor now?*– and entering a wider conversation that allows deeper listening to family stories. This heart-to-heart connection often supports decisions to form a circle, join in creating a family group, learn about what people associated with DFRS have learned about what it takes to compose a good family life, and take hopeful action. This is mostly not a self-conscious verbal process like a standard assessment process but a form of caring relationship that unfolds in its own time. It is a way of joining families that people come to experience as they live through it together; words struggle to express the experience.⁶

Often words simply fail to persuasively communicate what DFRS has learned outside the context of a continuing relationship with welcoming, experienced people who listen with an appreciation for family struggles and strengths. Though some people look at this as a problem to be solved by a smart marketing strategy, that does not seem to me to be the whole answer. There are indeed family accomplishments that could, and perhaps

⁵ Hearts can be touched even when the stories are mediated through video, as *In the Company of Others* has demonstrated. It's the listeners choosing to take the next step along the path that's harder.

⁶ Indeed, some people who practice this form of relationship are impatient, even frustrated at what they see as navel-gazing about something that is lived un-self-consciously. This is understandable but in tension with the lessons of difficult experience. It is possible to act with a good heart and follow false paths or deny signs of need to learn. Investment in mindful and compassionate critique is an essential safeguard, especially for the third stream: the work of convening and facilitating circles and supporting them to do the adaptive work necessary to develop good lives in community.

should, be patterned into statements and statistics that demonstrate the the Ministry saves money and generates multiple outcomes from its investment in DFRS. But I think the trouble is at least partly in the counter-cultural nature of DFRS experience, both in the context of typical human service narratives and in the context of the larger culture.

DFRS has invested significantly for many years in training by Wolf Wolfensberger, of happy memory, and his associates. Professor Wolfensberger's teaching provides powerful ways to understand the clash between the stories arising from DFRS' work and the dominant culture of society and its systems. In the interest of brevity (and because I understand the situation in a somewhat different way than Wolfensberger does), I'll describe the strangeness of DFRs' stories in somewhat different terms than his associates would.

In the encounter between DFRS and the themes that tend to dominate cultural common sense, stories about care for one another that finds strength in what is broken in all of us, the richness and depth of interdependence, and the practical power of sustained, faithful and loving collaborative relationships meet stories of self-invention, self-sufficiency and competitive productivity that feeds consumerism, taken-for granted to the point that they are seen as the whole objective truth and not as socially constructed stories that result in the exclusion and oppression of people with disabilities. These themes, and the fear and anxiety that they generate as economic and ecological crises push through layers of denial, dominate our economic and civic life.⁷

People with substantial disabilities are profoundly devalued by these dominant cultural themes and many families are left to cope alone and without access to what DFRS and others working in a different cultural space have discovered. This can lead them to invest their hope in systems that act, as if on remote control, to reproduce the dominant story in the service world. Individual choice is the highest value, independence is the goal, and the assertion of individual rights is the means to claim a place as a consumer of what the service system has on offer. While it is easy to facilitate families to enumerate complaints with the service system, the remedies are more likely to stop at more of the same: more consumer choice, better technological means to cure disabilities, more aggressive enforcement of rights and more clever marketing of

⁷ To label themes in the dominant narrative, I have borrowed gratefully from Walter Brueggemann (2012) *The practice of prophetic imagination*. Minneapolis: Fortress Press.

disability. (These measures are not necessarily undesirable in themselves but they are fundamentally incomplete without the felt support of the intimate social forms exemplified by circles and family groups to shape and sustain the journey.)

Living the experience of the action that emerges from circles and family groups makes talking to those who share the experience easier than talking about it to those who are not already on the journey. In part this is because the dominant cultural narrative not only devalues the people who don't measure up to its demands, it also debases the language of relationship in an attempt to turn every human act of care into a transaction that can be commodified, specified, measured and purchased. It rings true to insiders when a participant in our discussion describes circles and family groups as *manifestations of love and compassion* and another participant says, *Those words sounded flaky until I realized that they describe what I have experienced as making all the difference in my own daughter's life.* In a world overfilled with clever and sentimental marketing gimmicks, many people are unsure what to do when a story moves their hearts. Cynicism is an understandable response; so is enjoying the feeling and letting it pass without heeding its invitation.

The dominant culture demands and rewards stories and images that carry its marketing messages. It likes stories of cure or science in search of a cure. It likes stories that evoke pity. It likes stories of outrageous mistreatment or abuse, especially when they feed the appetite for political scandal. It likes short, happy stories that sizzle with how well its system's policies are working. DFRS family stories might occasionally touch these popular marketing themes, but they are mostly different, and the differences are what give them the capacity to touch people's hearts. Many DFRS family stories speak of genuine and encouraging progress in the directions indicated by DFRS beliefs and principles and they incorporate the reality of continuing struggle...

...the difficulty of fulfilling the vision of people in valued social roles in community life

...the incomplete project of building strong relationships that offer security as one generation passes responsibility to the next

...persistent shortfalls in funding that become more difficult to manage as the investment that family members are able to make in the work of providing support decreases

...the fruits and the costs of searching for the right thing to do using the lenses and methods of social role valorization and moral coherency and managing the nearly inevitable instances of being unable to do all that people deserve

...the practical problems and moral issues involved in family managed supports, especially recruiting, developing and retaining capable assistants.

It is the honest reflection of these continuing difficulties that give DFRS families' stories the depth and meaning that can touch people's hearts.

DFRS experience shows that to gain as much freedom of action as possible, families need support to tell their own stories in ways that join them with other families in figuring out what's needed for a good life journey together. This positions people to draw on the assets of the other families who have been longer on the journey, especially those families whose own journeys are coming to the stage of passing to the next generation. To get to this place, as one participant in our discussion observed, *you have to get rid of the world you live in in your head, take on a new mindset and join the journey*. Some who have experienced it describe this as touching a memory of a time of greater mutual care; others describe it as a vision of a desirable future.

Making this shift is hard work because it calls families to not just think differently but, most important, act against the dominant themes. In a culture that demands self-sufficiency, DFRS encourages families to invite others into their lives. In a culture that demands self-invention, DFRS invites families to see the resources and experience the hope that comes to light when people freely exchange their gifts. Against the grain of competition and consumerism, DFRS encourages purposefully inefficient use of time in sharing stories, collaboration and co-operative forms of organization, and asking a person's way into valued social roles. It takes courage to overcome shame when it is there, to face disappointment when people say no or things don't work out, to be vulnerable to other's trustworthiness.

One topic of our discussion exemplifies the distance DFRS' stories have to travel. In my grossly oversimplified form, call it the **Parable of the Once-Told Story**.⁸

⁸ Fairness calls on me to note that this parable is simplified from the perceptions of participants in our discussion. I have no idea beyond these perceptions of what was in the minds of those who crafted the policy.

Some earnest reformers asked families how they could improve the system. Sick of re-telling their family member's diagnoses and difficulties and the details of their history and circumstances from pre-natal time onwards at every new doorway the system sent them through, they said, "We do not like to tell this story over and over. We want to tell someone just once and have others who need the information get it from them."

The reformers thanked them for their input and proudly incorporated their response to this complaint into the system's transformation. Now families will only tell their story once every five years, to a courteous stranger with a list of many probing questions. The same questions for every family. Through a fair and objective process the answers to these questions will reveal how much money a family can wait to get from the system and the services they can buy when the money comes.

To make sure families only have to tell their story once, the system will not authorize the telling of family stories more than once and stories will be told in a standardized, monitored way.

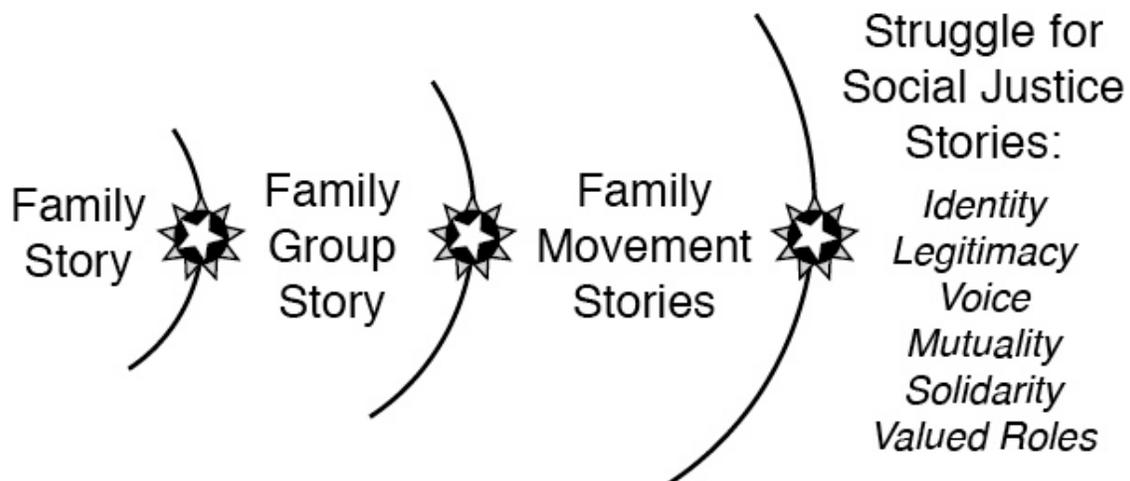
The parable suggests a common bureaucratic process. The system tackles a legitimate, if unpopular, public issue and justifies its solution in a way that can obscure the way the system is solving the problem. As an undesirable effect, the attempt to incorporate an extra benefit –in this case, not repeating a story– reduces the space that other good, non-bureaucratic things need to grow. Given scarcity of tax money it is reasonable to look for a fair way to spend the least amount of money necessary to meet the needs that the political process defines as legitimate. If this rationing function is clearly described, citizens can criticize it and advocate for improvements, including a better share of public funds. They can also figure out how to make the most of whatever money it does produce for them, as Deohaeko's members have done with a significant shortfall of service money for many years.

As the Ministry's multi-year implementation of system transformation rolls out, "tell your story once" is presented as an attractive feature of a complex rationing and efficiency mechanism involving DSOs , SIS assessments and other processes that are far from earning families' trust. The linear logic of transformation has no room for the lessons available from reflecting on DFRS stories. It seems reasonable to hold to a minimum the

number of times you are required to rehearse your family's case history to system and service gatekeepers (and to know that something real and useful will come from the rendition). But it would be a great mistake to imagine that under these conditions the family story is being told in any complete and meaningful way, or to demand that such a complete telling should be required in a rationing process. And it would be an even greater violation of what DRFS experience shows to reduce in any way the resources available to facilitate families in sharing their stories. From the earliest days of the Family Study Group, circles and family groups have demonstrated the power that emerges as families tell their changing stories again and again to people who have heard them before and want to hear them again, listeners who repeated stories the teller has heard, listeners who come to show up as actors in the stories they are hearing, listeners who become fellow participants in a bigger stories: the story of the circle and family group; the story of the movement of people with disabilities toward valued social roles; the story of marginalized groups struggling for justice. What magic there is in DRFS comes less from the content of family stories than in the relationships that grow in many stories' retelling in a climate of acceptance and deep listening.

What now?

Hope and sense of meaning grow when families see and feel the ways their stories connect to larger contexts.



The stories shared in family groups often lead to shared action. They also give each family a chance to understand their story in terms of the stories of the other families

they have joined. Discovering how their experience mirrors and carries forward the family movement provides a greater sense of connection still.

As DFRS visit to Romero House showed there other sources of hope and meaning to be met by learning the stories of other groups working for social justice. DFRS families can learn and take strength from stories arising from the efforts of other people who seek recognition and legitimacy for their identity as occupants of valued community roles, find influential voice for their concerns, act on the basis of mutual exchange of gifts and thoughtfully building a way forward on available assets, and make alliances with others who share their values. More involvement in purposeful learning from diverse others engaged in the work of building up what Martin Luther King called the Beloved Community should strengthen DFRS resolve and extend its understanding.

A better understanding of how DFRS works and a wider vocabulary for expressing its impact could come from making time for inquiry. Two possibilities suggest themselves for a start.

- Dialog interviews with families that ask how DFRS vision, beliefs and principles have emerged in their family life. Dialog interviews are occasions for focused deep listening, not for evaluation. Listening to family members reflect on the ways they are living DFRS beliefs and principles in their own words should increase understanding and extend the stock of powerful ideas and images.
- Critique of the effectiveness with which DFRS supports families and family groups. This process could begin with a shared exploration of the ways facilitators support the emergence and continuing action of family groups.