Response to the Joint Developmental Services Sector Partnership Table Document, *"Transforming Services in Ontario for People who have a Developmental Disability"*

From Deohaeko Support Network

We are a group of eight families from Durham Region who came together about 13 years ago to think about the future for our adult sons and daughters who have a developmental disability. Our story is unique and significant for several reasons:

1. We have over ***ten years of solid experience in innovative housing and individualized supports*** for our sons and daughters on which to base our observations, suggestions and points of view.
2. We are evidence of what was possible at a time when both federal and provincial levels of government were supportive of creative and unique housing and support options for individuals and families. During this time we:
    - ***built a federally-provincially funded housing co-operative*** in Pickering with 105 units, seven of which are still home to our sons and daughters, and the others used by a wide range of ordinary people in Durham Region;
    - received initial ***funding which we individualized*** in order to design supports that would be uniquely suited to each of the seven people involved.
3. We have developed ***a unique model of funding*** based on individual family accountability, asset-based support plans, sharing of funding between families mid-year when necessary, and a paid facilitator in our core budget. At the same time, we do so on an inadequate budget that has actually decreased over the past ten years, supplemented by Bingo fundraising.
4. We have over ***ten years experience with a paid coordinator*** (facilitator) and have learned how to support and guide this role which has been a crucial element in our accomplishments, our overall stability and our hope for the future.
5. We have developed ways of ***supporting our sons and daughters based on people coming to know and care for them as full and unique individuals***. We do not arrange any group or congregated support. Paid Supporters only work with one family. No individual ever receives 100% paid support. People who spend time with our sons and daughters are family members, friends, neighbours and paid Supporters (hired and guided by the family).
6. Additionally, we have ***written four books***, established an ***endowment fund*** with the Community Foundation of Durham Region, are winding up a five-year ***Trillium project***, and remain at the heart of the intentional community within the co-operative community.
7. Most importantly, ***our sons and daughters are living full, contributing and meaningful lives within the heart of their co-operative and greater communities, and have done so for the past ten years.*** They hold a wide range of typical and familiar citizen, work and recreation roles. Several people own their own small business. They are connected to a variety of other people in casual and intimate ways. Our sons and daughters are the strongest

evidence that our unique approach is working for them and for our communities.

The following are our thoughts on various aspects of the “Transforming services” document

1. Individualized Funding

Our experience shows us that individualized funding means individual support plans, individual goals and dreams, individual homes, and individual lives. Although our sons and daughters have chosen Rougemount Co-operative as their home, each person lives separate and distinct lives. Each person has their own apartment. Apartments are at all levels in the six-storey building. Some people prefer to live up high, some at ground level. Some people prefer the sunny and livelier side of the building facing busy Kingston Road, and others prefer the shady, cool Rouge Valley side. People have chosen one, two and three bedroom units according to their wishes to live alone, with a room mate, or otherwise. One person has even chosen to live elsewhere after seven years in the co-operative experience. Each person’s apartment reflects unique tastes, preferences, and living styles. People receive different amount of formal and informal supports according to their wishes, plans and support requirements. Individual roles at home and out, their schedules and their daily plans vary greatly.

We believe it is important that individualized funding is a situation where families remain in control of the money throughout. Families can then be in control of deciding priorities, recruiting, hiring and training paid support, and changing plans as needed. This has allowed the families in our group to plan and support according to changing family and individual situations. We have found that not only are adjustments needed as individual support requirements change, but also when the family situation changes (parent health declines and the parent cannot provide as much direct support, a supportive family member moves away and others can only take over partially, the whole family goes on vacation and less paid support is required).

The money should not be used to purchase services elsewhere, because then the family will lose control once they enter into a service arrangement (i.e., control of choosing own staff or support, defining what the day looks like and when and how to change it).

We ask that 25% to 50% of all new monies from the Ministry be designated as individualized funding as we define it.

2. Roles and Responsibilities

a) of community
It is our profound experience that people must first be PRESENT in their community in typical, familiar and valued ways - only THEN, will ordinary people in community come to know the person and welcome them as unique and contributing individuals. We know from our experience with the Rougemount Co-operative and in the Durham communities where people are active, that presence (as described above) will change community members' perception of the disabled person and allow them to welcome them as a true part of the community.

This means that people cannot live apart from the community generally (even in group homes) and "enter" into the community for "outings". They must be a regular part of community in their everyday lives. They must be seen to have a real home in community, to contribute in typical ways (work, volunteer, study), to recreate in familiar places, and take part in civic responsibilities.

This also means that the government cannot mandate welcome and acceptance by community members or associations. They can mandate the resources, the education and the supports which will allow people to be present with the support and accommodation they may require, but they cannot mandate welcome.

b) of individuals with a disability
It is impossible for individuals to fulfill their responsibility as citizens unless they are present in community and supported as necessary to hold their roles as full citizens.

c) of parents
Parents and families work hard to ensure that their sons and daughters have a home (either with them or elsewhere), have extra money for winter clothing, have money for short vacations or breaks, have access to ODSP and ensure that all requirements for reporting are met, have transportation and support for medical appointments, have help to find a job, other work, or a way to spend their days, have access to some kind of recreation. Parents take on some of these responsibilities for all of their children for some periods of their life. Parents of a person with a disability accept these responsibilities and more for as long as they are alive and able, and then, to the best of their ability they try to arrange secure financial futures for their sons and daughters. They do so because they love their children and feel it is the right thing to do.

On top of all of this, it is hard – impossible, even - for families to afford to pay for the support requirements of their sons and daughters. Dollars for support need to come from elsewhere, since often, all other support often comes from or through families.

Families are asking for a hand up, not a hand-out. Government and the rest of society need to be aware of and appreciative of the long term support and resources that many families happily share with their sons and daughters. Ongoing support costs are only one part of the support picture for people with disabilities. The families (and others who come to know and care for people) are taking their full share; the rest of society needs to take their share.

Our discussions with many people in our communities over the past ten years have shown us how much ordinary citizens benefit from a relationship with a person who has a disability. Our communities gain in strength, flexibility, tolerance and creativity when they stretch themselves to get to know and welcome someone who appears at first to be a bit different. Ordinary citizens who have benefited from these relationships would not doubt the value of using their tax dollars to pay for one part of what it takes for that person to be a part of the community.

3. Support

People are best supported by those who know them well, who care for them deeply, and who are guided by those who have made a long term (life long) commitment to that person. The best ways to ensure this kind of support arrangement in our experience is as follows:

a. People who are recruited to offer paid support to an individual are hired on an individual basis for their unique skills and qualities that match best with the individual. The individual who is supported must be an active part of deciding who will come into his or her home.
b. Supporters only work with one person at a time. In this way they can constantly think about providing genuine, respectful and creative support at all times.
c. Supporters only work with one family at a time. In this way they do not develop a “caseload” mentality but can focus all of their attention on one person.
d. Unions will not usually work under these circumstances. They cannot allow the individual and family to decide on who is to work, at what hours, and how often to change that arrangement.
e. At least as important as finding good Supporters, is the ongoing development of a caring, understanding, and motivated network of friends, extended family, and others who make a longer term commitment to the person. Supporters will be guided in their work and their attitude by this network (or part of it). Parents are an essential part of this network but not the only participants.

4. Safety and Security

We must focus on helping people with disabilities to have a wide range of relationships with many different people in their community, especially personal, close relationships with typical, valued citizens of the community. The building of these relationships must be the first priority set by parents and members of the support network, and therefore a guiding message that informs the work of the paid Supporter.

Relationships – in particular relationships with typical, valued citizens who care deeply for them - will keep the person safer than any service, programme or policy.

Safety and security depend most on a) being present in community in typical, familiar and natural ways and b) being surrounded by a network of people who love and know you.

5. Models of Funding

Instead of needs based, or deficit assessments, look at using ***asset-based support plans*** developed by families, with coordination by an independent facilitator. When dollars are limited, the amount awarded to the plan may be pro-rated against that plan (i.e., 60% of the plan may be funded). The fact that the full dollars are not available, does not change what a person requires in terms of good support for a good life.

This is the method we used to request funding ten years ago. It allows all families to clearly state the full support requirements of their son or daughter. It allows a way to clearly show how family and friends plan to provide natural support into the future. It allows families to talk about their sons and daughters in positive, clarifying ways instead of focusing on difficulties and needs. When a family feels they have designed a plan that is secure and flexible for their family member, they do not worry about whether another family receives more funding or not. Within Deohaeko Support Network, all of the families shared their plans with each other and families made changes based on the input of others who knew their family member well. This served as a strong foundation for the next part of our funding model – collective sharing of funding.

Consider funding small groups of families who are able to ***share their individualized funding collectively***. In this part of our funding model, each family receives their agreed-upon allotment (either dictated by the support plan or portion thereof) on a yearly basis. Part way through the year, families share information about if they have a few extra dollars (due to unforeseen staff shortage, illness where less paid support was used, etc.) or need extra dollars. Dollars are then shared among the families. At the end of the year, all families revert back to receiving the original allotment.

This sharing of funding has allowed us to be very creative and flexible with our funding. We have been able to ride out some short term crises without extra funding because of the flexibility and generosity of the group. In essence, giving up some dollars one time when one has a surplus is easy, since they return to the full amount the next year, and they may get some extra dollars when they most need it.

We believe that the crucial elements to this sharing of funding include:

a. Families know and trust each other through hours of discussion and work together.

b. Families know each other's sons and daughters well and can understand their support requirements.
c. Families have discussed and worked through having a common set of principles and beliefs about the good life, support, how to spend funded dollars, the role of family, etc.
d. Families have had input into each other's support plans and fundamentally agree with each plan of support.
e. A common coordinator (or facilitator) who is accountable to the group helps each family individually so that all support plans use a common way of defining support.
f. Each family's core allotment of funding represents an equal portion of the whole, i.e., each family receives 60% of their support plan costs (which means if you add up all of the support plans, the family group as a whole only received 60% of their total funding request).
g. Whenever a family gives up a portion of their funding, or receives a new portion of funding, the reasons for such are discussed openly.
h. Whatever sharing takes places is simply one-time, and on April 1st of the following year each family reverts to getting their core amount of funding.

Funding to families needs to be ***secure***. It must be an amount that we can count on and plan around into the future.

Funding needs to be ***flexible***. Funding for support is always in relation to both the support requirements of the individual *and* the current status and health of the family. Family illness and aging can affect support requirements at any time. "Transition" can happen at any time for people – not just during set phases of one's life. Funding must be able to accommodate these times. Funding should also take into account the years that a family puts in large amounts of personal support, so that there is a way for the government to augment support when the parents or main family supports (all unpaid) become ill or are aging.

Funding needs to be ***portable***. One of our daughters decided to move out of the co-operative and into another home of her own choosing. Her support dollars went with her because she is still in the same city. The dollars should stay with her even if she decides to move to Niagara Falls.

Finally, funding needs to be ***adequate***. Over ten years ago, we began with an amount of funding that was significantly less (we received a little more than half of our request) than what was required by our sons and daughters to live full and contributing lives. Due to our high energy and commitment as parents, our faith and ability to encourage natural support through friendships with others, and our unique sharing of dollars we have nonetheless been able to support our sons and daughters and to help them follow many of their life goals. During this time, two of our fellow parent board members have died and significant health issues affect at least two other members. We are proud and confident of the ongoing support that other family members and friends will provide into the future.

However, we feel strongly that it is time that the Ministry start to provide some of the essential support dollars that our sons and daughters have always needed and we have provided for at least the past ten years. In fact, if we look at the past ten years alone, we have calculated to have saved the Ministry over $2.3 million dollars by not having our sons and daughters enter into more costly “traditional” group home and sheltered workshop settings. We have managed well for many years. Now we need the government to support new family members who will take over significant portions of our role, but who cannot allot the same amount of support time due to their own family demands.

6. Facilitator/Coordinator

We organized ourselves to find and hire a paid coordinator from the time that we received our very first fiscal dollars eleven years ago. Depending upon funding, government cutbacks, number of families involved (we’ve had a few adjustments in the last 13 years), project funding and other issues, we have had one to two part-time coordinators at all times. We are possibly the family group in Ontario with the longest running experience of using a coordinator model.

We know that this is a key position for families and family groups like ours. A coordinator helps each family individually, and the group collectively, map out and hold a vision for the longer term, while making sure that what happens now is sound and thriving. In our experience the degree of helpfulness and significant support from the coordinator happens when there is a low coordinator to family ratio. Currently, our ratio of seven families (where age and health issues are prevalent) to one 25-hour per week coordinator (with experience) is sufficient.

Our experience tells us that a facilitator or coordinator must be hired by and work for the family or family group– that is, unencumbered by either agency or government association. This independent nature of the coordinator will ensure that the family remains in control of the priorities, goals, and life directions together with their family member. It is important to understand the ongoing mutual nature of this relationship. The family constantly teaches the facilitator and keeps them grounded. The facilitator constantly offers ideas and alternatives that are easier to see at an arm’s length.

In our experience, we would like to say that the unique relationship that may develop between family members and their coordinator, as well as the highly satisfying nature of the work, has led to our own coordinator remaining with us for well over ten years at this point.

We offer an excerpt from our own writing and reflecting on the role of the coordinator in the Appendix B at the end of this document. This may further broaden the understanding of this important role to families.

7. Support for Innovation

We believe that there are many kinds of innovative and creative solutions out there for many kinds of families and family situations in Ontario. We think that it would be important for the Ministry not to try to offer families two or three or five solutions that seem to work well now. Instead, the Ministry should offer a flexible, resourceful framework in which families can create their own alternatives in housing, work, recreation, home and simply finding their place in community.

8. Priorities

As we have stated above, we strongly feel that a strong component of individualized funding within Ministry policy guidelines would be the best way to allow individual families and family groups the opportunity to set and work on their own priorities.

9. Other

- Education and training for paid Supporters – The Personal Support Worker training is inadequate to most of the day-to-day attitudes and approaches required by individuals with disabilities who are interested in leading full and contributing lives. Personal Support Workers do not learn how to help someone build a home, nor do they learn how to assist someone to be involved in their community as full members. Most Developmental Services Worker programmes – with the notable exception of Centennial College – are equally inadequate to family situations. Most placement situations are unable to take into account family needs and situations. We wonder if there is not another way to explore training and recognizing education within families – perhaps through an apprenticeship model?
- Pay issues for paid Supporters – most families do not receive sufficient dollars to pay Supporters competitive hourly wages. We can offer $12 or so per hour, and many other families can pay much less than that. Group home, sheltered workshop, and educational staffing rates are much, much higher – usually from $17 per hours and upwards. By the same token, many families do not manage to find ways to pay employment related costs and are forced to hire Supporters on contract rather than as salaried employees. However, the skills, energies, attitudes, and strategies required by families is at least as challenging as that done by higher compensated agency staffing.

In conclusion, we would like to offer you a number of written materials that we feel will add to the understanding and depth of the members of the Joint Partnership Table regarding the range of opinions and issues that we have raised. These materials include:

1. *Individualized Funding book* – a book we wrote about our first experiences with individualized funding.

2. *We Come Bearing Gifts* – a book that looks in some detail at our first seven years
3. *On Our Own …Together* – a recent book that explores our experiences and learning about financial and person security for our sons and daughters into the future, including the establishment of our endowment fund.
4. *A vision of a good life* – an explanation of the kinds of things we mean when we talk about our sons and daughters wanting to live full and contributing lives. (Appendix A)
5. *Our experiences with a coordinator* – an excerpt from our newest book to be published in December, about our experiences with assisting people to find their places and roles within a welcoming community. (Appendix B)

We sincerely hope that our ideas, experiences and opinions will be well considered by the Joint Partnership Table as it continues its work toward transforming supports and services for people with a developmental disability in Ontario.

Please feel free to contact us for further discussion, comments, or ideas. Additionally, we are always happy to put the kettle on for tea if a visit to the home of one or more of our sons and daughters would shed some further light on our way of living together in community.

Yours truly,

Helen Dionne, President
Mary and Clive Bennett
Linda Dawe
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Appendix A

A Vision for Life

It is important - even essential - to hold before us a positive, well-articulated vision of a good life for each person. This vision can provide us with direction in times of confusion when one must choose between many choices. The vision can provide us with ideas and possibilities in times of trouble, with a way of setting priorities in times of scarce resources, and with hope. A clear vision which is communicated among and shared by the people who care for the person most is our best hope for a good life for them, now and in the future.

We want this person's life to contain the same things that all of us would include to describe a good and meaningful life for ourselves:

- a place to call home
- safety and security in one's home and wherever they go in their community and wider abroad
- connections to family, friends, and a wide range of acquaintances - people who value them for their own unique combination of character, gifts, talents, and strengths
- a sense of belonging - people who value their presence and miss the person when they are not present
- a place or places to give, participate, and contribute in meaningful ways that are recognized, appreciated and welcomed
- spending their days in personally fulfilling ways
- continual opportunities to grow and expectations that they will grow and learn throughout their lifetime
- respect of those with whom they come into contact
- the opportunity to make good, well-supported choices and to be involved with governing the direction of their life
- good health as a result of living a healthy life style
- a few close and committed relationships with family members and friends, and an ever-widening circle of those committed to be with them on their life's journey
- a way to communicate with at least a small circle of people who understand them well and care to listen to the deeper messages within their actions and responses to situations
- hope for the future
- the opportunity to work on a few of life's dreams at any given time
- a satisfying spiritual life

We are committed to finding ways to achieve or sustain the vision of this life for and with this person.

Appendix B

The following is an excerpt from a copyrighted book by Janet Klees, to be published in December, 2004. It is to be used for information purposes only. Please contact Janet Klees (416) 261-4536 for discussion about copying or sharing in other venues.

Coordinators

A coordinator can be any paid person who provides one or a number of non-direct support roles to the family or family group. For some, this is a person who has some functions for the family group as a whole (proposal-writing, preparing funding accountability forms, bringing common concerns and experiences to the whole group, general recruitment). She then may have other roles in which she supports the individual families (helping individual families apply the group's general philosophy and principles in practical situations, assistance in interviewing, helping maintain circles, help to orient and guide supporters, etc.).

In other situations, the coordinator may work for one family and simply have a few non-direct support duties in addition to her direct support roles. She may be asked to coordinate the schedule of paid and natural support, to handle budget and finances for the individual (with appropriate accountability), or to be the person with whom the family enters into discussion about what the supported person does with their time, etc.

We have used a coordinator model from the very beginning of our funding, ten years ago. There has been much interest in how we manage, use and think about this position from other families and family groups since we have worked in this way for a significant period of time. Therefore, I am going to devote some time and attention now to providing a bit of an overview of my role – my tasks and the approach I take - with Deohaeko Support Network. Our coordinator model follows the first example above, where I have both roles with the family group as a whole, and then other roles with the individual families.

Holding the vision with the family

A large part of my role is to know the individual and the family well enough to be able to help them all articulate the vision that they hold of a good life for their family member. This does not happen quickly, but rather is an unfolding process that happens over a number of years. Listening to the individual is just as important a piece as listening to the family. Over time, I begin to more fully understand where their dreams and goals lie in terms of home, work/community contribution, relationships, leisure, spirituality, personal learning, lifelong achievements, health and well being, and more. I also begin to understand which parts of this vision are still unfolding as the individual is learning about all that life has to offer, and which parts are already firmly set. For Rob, Jon and Tiffany I have helped to put this vision in writing. I am in the process of doing so with John and Brenda. I may yet do so with the others.

Part of the coming to understand the vision, is that I then become one of the people who hold the vision in the person's life. In my experience, not many people in anyone’s network have the time or the privilege to sit long enough with a family to hear the vision. During my ten years with these families, I believe that I have done so. With that immense privilege comes the responsibility to hold the vision along with them. My responsibility is to be one of the people who hold that vision, keep it safe, and help the family pass it along to others who will either honour it, work within it (Supporters), or begin to share holding it high.

Some of my most recent work is figuring out with families how to pass this vision on to the next generation who will be entrusted to ensure that the disabled family member live a good life.

Safeguarding most valued roles; protecting vulnerabilities

Roles are an important way for other community members to understand and value people with disabilities. Holding typical, valued, and recognizable social roles makes it more likely that community members will form relationships that are mutually enriching. It takes hard work and focus for people with disabilities to take on some of the life-defining social roles that most of us take for granted. At the same time, the same social forces place stereotyping negative roles on people and make them vulnerable to abuse and even violence. My understanding of these social dynamics, together with my deep care for the individuals that I have come to know, mean that one of my important tasks is to safeguard the current positive social roles that people hold.

I understand that the family roles that people have are vitally important to people’s well being. I try to find ways to uphold and support efforts to strengthen and fill these family roles in natural and positive ways. I know that family roles such as son or daughter are already held in very positive ways. Sibling roles may not be as strongly held and we need to find new ways to fill them. People are beginning to hold some new roles as aunt, cousin, and step-son, as well and these offer lots of scope for new directions. Within circles and smaller discussions, we try to find ways to move forward in these roles. Sometimes, I simply am there to remind people that these family roles are there and only need to be embraced in small, natural, and typical ways (birthday cards, Christmas gifts, telephone calls).

Many of the community roles that people hold right now have been acquired since my time with the families, and I am fully aware of the richness that they have added to people’s lives. I spend some time helping to safeguard these roles through tough times. When there is a transition of Supporters, when there are other problems in the family, or when medical or emotional issues arise, these roles are often threatened. I try to help make sure that this is only a temporary situation, or to provide some other way of holding the role. Sometimes, I do this directly, and often I just keep tabs on who is doing this in the interim.

When Tiffany’s baking business was in some distress, her small advisory group met and we discussed how much the roles of entrepreneur and baker had added to Tiffany’s life.

After much effort, we found ways to scale down the work of the business without closing down completely, and with the intention of starting it up again when the right conditions prevailed. In addition, we talked long and hard within the larger circle and in smaller groups about what kinds of roles Tiffany might begin to explore to compensate. Her current roles as young artist, and Rouge Valley naturalist were then born, and have grown to add much to her life. Sometimes I am there to help safeguard a role; sometimes I am there to make sure new and strong roles are ready to be explored as replacement. It is not to say that these good things would not happen without my presence, but rather that it is *my role* to keep Tiffany's positive roles at the forefront of our thoughts.

I know that powerful, positive roles are a protection for the vulnerabilities that people possess. Sometimes I use this knowledge to balance out a strong negative perception that people may hold about a person. When Brenda is upset or anxious, all of her neighbours are likely to hear her distress. We know that this may lead some people to fear Brenda or to perceive her as a threat or a menace. To compensate and to remind her neighbours of the other side of Brenda, we try to find ways for her to meet her neighbours under positive circumstances. When she is invited to Tiffany's apartment for a gathering or party which always involve many of her neighbours, Brenda is invariably happy, gregarious and good-natured. We know that her neighbours need many chances to see her in this light, so we strongly encourage her to accept such invitations. Elizabeth, her mother, Brenda and I have discussed at length the conditions under which she is most likely to attend the event. As much as possible we try to bring these conditions about.

In many other ways, I work to promote the valued roles that individuals hold, and to protect against their vulnerabilities. I talk to people a lot. I talk to individual Supporters when I can and reinforce their understanding of these dynamics. I talk to neighbours at Rougemount and try to counter their negative perceptions with good information, while promoting their positive roles and contributions at the same time.

As a resource to accessing the community spaces

I help family, circle members and Supporters figure out how to find and assess good places and roles in the community. Sometimes this is done in small discussions with the family and the Supporter, and sometimes within the circle. I don't have many personal connections in and among the clubs and networks in our area, but I do have a good idea of how they are organized and where one might go for further information. I try to help the Supporter or family work through what they are actually asking for. I know that effective asking is based on asking the question to which the other person is able to say YES. The individual is involved in these discussions as often as possible – most of them take place in their home.

Often we begin with an interest that the person has shown or that the Supporter feels is worth exploring. I help to figure out all of the potential roles that people hold who share this interest, and then we work on all of the possible activities that are undertaken in these roles. Chapter 7 explores this process in more detail. It is an effective way to discover the many ways in which one might engage with their community.

Depending upon my time, the current skills and understanding of the Supporter, and the situation in general, I may offer to help with initial fact finding or contacts. There are several more steps outlined in Chapter 7 that may lead to a person exploring or holding a new role and engaging in new activities in their community. I may speak to Supporters as they work their way through this process, I may do a piece of it myself, or I may just be sought out as problems and difficulties arise. I do much of my own reading and following the events in our community, and I often pass along information about new groups, open houses and other opportunities for engagement.

Part of my role during this whole process is to model, teach and remind us all about the principles of social role valorization. I try to ensure that the roles sought are typical and valued, that the community settings frequented are valued in the community, that the activities enhance people's competencies and image, and that people can be reliably present on a intense basis. I try to find ways to remind Supporters that relationship building is key to their role and that must be vigilant in their efforts to invite, encourage and welcome people who are drawn to the person they support.

Helping with orientation

I help families with different parts of the orientation process. For Donna and Brenda I am very involved in the entire process. For Tiffany and Jon, I often spend individual time with new Supporters talking about social roles, their roles and the principles behind our approach to support. For some of the others I do a small piece, or a one-time discussion. When trouble arises, I often work with the family to help the Supporter figure out the next steps.

Promotion of neighbourliness at Rougemount

I am at Rougemount at least three or four times every week, and although I am not very involved with the local politics, I make time for talking with neighbours about everyday things as often as possible. In this way, I try to keep abreast of the kind of information that I would want to know if I were living in that community. I try to bring this information back to the people that we support.

Quite often the information is familiar to them but a Supporter might not think through the implications. When it was announced that all of the locks were being changed on all of the unit doors, neither Brenda nor her Supporter at first understood how this might affect them. When I found out that changing the locks would mean men coming to hammer away at her door that was not broken, we knew that this would be difficult for Brenda to understand. We also realized the difficulty that having a new key would pose for Brenda. An everyday occurrence for most co-operative members (indeed also for the Supporter) was a situation that needed to be well worked out for Brenda.

Sometimes a person knows about the information but they are not sure what to do with it. When Marje was sick at home, people did not know if they should bring her a bowl of soup, or leave her alone in peace and quiet. From talking to Marje, I could help people think through what a welcome gesture to Marje might be.

Sometimes the person has not heard the information, and upon hearing it, knows just what they want to do. When someone in the community has died or has a close family member who has died, Donna is always the first person to buy a card and go around to get neighbours to sign it. Sometimes I am there to give her that information. More often she is the one that tells me what is happening.

Often, the individual would need significant support to react to news of the co-operative in typical, neighbourly ways. This is where I sometime try to play a role too. One day, a woman was down in the office very upset because her glasses were broken and she couldn't make it to the optometrist by bus before her kids got home from school. I knew Tiffany was home that afternoon, and I knew that she was with a Supporter who had a car. I asked the woman to wait while I checked something out and confirmed that Tiffany could move her plans around a bit and go with her Supporter to take this woman to her optometrist. I told the woman that her neighbour in #110 would help her out. Now, clearly, I could have done the same thing myself. But I knew that Tiffany might well have taken this opportunity herself if her time was free, and since she was the neighbour in a community wanting to promote neighbourliness, she was the better choice.

Many times these hallway conversations tell me wonderful stories about many people in the co-operative. Keith who has provided maintenance for the building came to tell me about the great relationship he was developing with Brenda. I had a chance to put some of the extra repairs he needed to do for her into the context of Brenda being one of the people for whom this building came to be. Extra repairs would always be needed and that was okay. I heard about Keith being there the day that Matthew fell and broke his tooth. I heard about Rob turning up at Hilda's and inviting himself inside for a cup of tea.

People also use informal opportunities in the hallways and lobby to let me know about their concerns, often at an early enough stage that we can do something practical and immediate to improve the situation. In this way, I have heard that Matthew went out without mittens on a snowy day, that Brenda was up at 11:00 in the lobby last night, that Jon's Supporter was awfully terse with him on the elevator, and that Caroline Ann came up for tea during the thunder storm last night. Most of these situations are easily looked into and I can bring some practical information back to the neighbour in a short time. I could tell them that Matthew was going out to a parked car. I could let them know that another neighbour saw Brenda, walked her home and stayed for a cup of tea until Brenda seemed ready for bed. I could say that it was good for Caroline Ann to feel so comfortable with them that she would choose to go there with her fears about storms. More importantly, however, is my joy at people's concern and attention for their neighbours. I let them know that caring about others in this way is helpful and positive. And, in the situation with Jon's Supporter at the time, the information was very important for the family so that they could keep an eye open and ensure Jon's well-being. In my eyes, this is community working just fine.

Keeping track

One of the things that people laugh at me good naturedly for is the fact that I am always on hand with paper and pen, taking notes, recording. It is partly my nature that I think best with a pen in my hand. But it is also one of the ways that I contribute to the families and the group as a whole. I keep track. I keep notes about decisions that we have made as a group, things to do, good ideas to try out, and commitments that we have made to each other. Sometimes, I am sure, this makes me merely annoying. At other times, it is a part of me holding the big picture. If I keep track of much trivia, then the families don't need to. It's there for all to see, and much of it is copied, but it is not theirs to keep track of at the time. I can play that role.

I keep track of things like funding proposals, which includes writing them together with the families, and producing reports as necessary. Not only is this an administrative load off families, but it ensures that our requests are made in a coherent fashion, based on our principles which we have all worked on together. I also keep track of the accountability formats for our transfer payment agency. This only means that I provide a global record of the fact that all dollars received went out to families every month; the families maintain their own records.

I also keep track of some things in bigger ways. I have helped at least three families articulate a written vision for and with their son or daughter. These have developed into full-scale binders of information that we call, "All about Tiffany.." The majority of the information in the vision and in the binders come from the families themselves. It is full of their idea about content, scope, details and strategies. My part has been to introduce a format, organize the content, and to try and write the wording in ways that fully reflect the original intent, our basic principles and values, the integrity of the person, and the uniqueness of this family.

I keep track on the writing of documents like our Philosophy statement. This document has come about as a result of hours and hours of discussion among family members. My task was to try and record the discussions and then to produce many drafts of a document that reflected the ideas of the families. Each draft was then edited and subjected to more discussions and changes. My role was indeed to keep track.

Trying another way

When things go wrong, as they often do, I spend a lot of my time with people trying to figure out what happened and what to do next. To me, this is more than a brainstorming-trouble-shooting role. This is where I have to have the strength and the ability to go back to our core principles in the middle of chaos and calamity. The family is often in the eye of the storm, torn between seemingly impossible choices or alternatives. I have a measure of distance that I try to use to help me find balance and direction from the things that we believe in. We often cannot follow the paths of those who have gone before us, because we are walking new ground. But we can make sure that everything that we try is at least in the context of the principles that we have set for ourselves. Some of the questions I ask myself and the family are:

- This may not be good but are the alternatives worse? If yes, then hang on to this position and ask for more time.

- What happens for typical people when they find themselves at this point in their lives? (They see a doctor, talk to a friend, start again, let time heal.)

Brenda went through a period of great emotional distress and anxiety about a year ago. Many of the people around her wanted to put her psychotropic drugs to “manage her behaviour”. Her mother knew and I agreed this was not the answer for Brenda, and we feared that the sensitivity she showed to other medication might in fact cause these kinds of drugs to backfire, placing her farther and farther into the drugged world. During many deep discussions with her mother, Elizabeth and I decided that we thought that Brenda was having fairly typical reactions to several things in her life. There had been a great turmoil of support over the past five months, with a number of Supporters leaving and that uncertainty was very hard to handle. Elizabeth had been very, very ill with a flu a couple of months before and had not seen Brenda very much at all. Brenda had reacted very strongly to her father’s death years ago, and often talked about her fear of her mother dying. She must have been feeling that fear very strongly. We felt that Brenda might be experiencing symptons of early menopause that showed up in family history.

We tried to put ourselves in Brenda’s shoes and then wondered what we might do if we found ourselves in a similar situation. It was clear that Brenda’s emotional distress was acute much of the time and we did want to find a way to help her to feel better. We thought that for ourselves, being people not inclined to take medication for our ailments, we might consult a homeopathic or naturopathic doctor. And so, following the word-of-mouth advice from a colleague, Brenda came to meet Dr. Joe Kellerstein. Dr. Joe listened and asked questions and listened some more. He helped Elizabeth draw parallels between Brenda’s showing of rage and that of her grandmother. He helped us to see aspects of learned behaviour in her patterns of anger. He gave Brenda a very low dose of remedy and then taught us to observe Brenda well. We learned to look for signs of upset and reasons for upset, changes in how she showed her anger and symptoms of other good things happening in her life.

Life is not perfect for Brenda and those who care for her. But nowadays when she has one upset, it no longer means that she will have a day full of upset. Upsets rarely interfere with the day’s plans anymore. We continue to see moments of anxiety and anger, but we also see some new highs. Brenda likes to sit and focus on being read to from fairly complex chapter books. Brenda is producing some art that she feels proud of and happy to frame and give away. We look at Brenda and her emotional state. We understand that her upset and rage might come from a combination of factors. Some we have control over and some we do not. This has been a rocky road, fraught with contradictory advice from good people. Elizabeth, Brenda, the rest of her family and I have chosen a path that is not easy for many others to accept or believe in. However, it is a path that has honoured our principles. It is a valued choice that we would make for ourselves; it is not experimental any more than trying psychotropic drugs on a woman who has not had them is experimental. Brenda’s uniqueness has been upheld – we know that she needs and demands to be supported in genuine ways and we strive for that. We have accepted a part of the responsibility for her anxiety and anger in acknowledging that the support for her is still imperfect.

Through this process I have also gained some insight into what helps me when I am with Brenda and she is upset. I apologize. I tell her that I am sorry. I am sorry that she is upset. I am sorry that I confused her in some way and I don't know what. I am sorry that I can't figure it out. Then I am silent. And then she is okay again. I think in the space that we allowed ourselves to pull back from medical answers, I have found out some more about Brenda.

I think that Brenda will always be a person with a volatile nature. But her highs are much higher than her lows, and it is in her highs that you come to love her. On a day that I rushed in and said in passing that I had forgotten my lunch, she brought me an apple. It's my last one, she smiled. On a day of a very big upset, she sat down and made a remarkable replica of a flower in pastel. Makes me think of an artist's temperament. Brenda brings gifts for Matthew, gifts for Hilda, flowers for her Mom, and goodies for many people. How can we take the edge off her anger without taking the edge off her heart?

I don't know what the future will hold for Brenda in terms of effective ways to help her feel relaxed and calm. I only know that I will continue to move with Elizabeth, Brenda and other family members to choose ways that uphold our principles. These allow us to see Brenda as a unique individual, choose alternatives that typical, valued citizens would choose first, and recognize that at least part of the reasons for Brenda's anxiety lies with factors external to Brenda herself – poor support, support that does not feel right, and inconsistency in support.

Helping with recruitment

Over the last years my role in helping families find people has changed quite a bit. Until about a year ago, I or someone in my position, really took charge of the initial steps. I posted notices (drafted together with the family), received resumes, did telephone screenings of all resumes, and passed along vetted candidates to families where the request seemed to match the resume. I then went on to assist only occasionally with interviews, references and letters of offer. This always varied from family to family.

Over the past three or four years, we have tried in vain to hire a person to take on this concrete assistance to helping families find new Supporters. We believe that it is very hard to do this part of the job in isolation from really getting to know the individuals and their families. In the past year, I have had less time to devote to these tasks and families take on a bigger part of posting notices and looking for Supporters. At the same time, there are less places than before to post openings and expect a flood of resumes. Searching for Supporters is a less formal process than a year ago. As a result, more of our time is taken up in word-of-mouth recruitment. This means that resumes and telephone inquiries go directly to families as often as they come to me. The resume and telephone screening parts are now shared more directly with the families.

Plan board/family retreat focus

As part of our annual renewal, all of the family board members go away on a one and a half day retreat every November. We have carried out this tradition for ten years. My part in this event is to help the board plan a focus for the year's event, and then to implement some creative way to initiate discussion of the issue. Over the years, we have been fortunate enough to work with two coordinators (due to a small funded project) three or four times. These have resulted in dynamic, creative events with a lot of planning and pizzaz. One year the board was kidnapped and forced into leisure pursuits of frivolous kinds. Another year, we created a whole game in order to re-create a scenario to help us choose the right kind of endowment fund to meet our needs. On my own, retreats may be less glitzy, but still provide creative ways for the families to talk about future plans, assess past successes, tell stories, and solve bigger problems.

Being with people

There are times when we are temporarily stymied. We can't find the support, or the role is not working out, or the people around just don't get it, and in the end the person is let down again. At these times, the single most important thing that I can do is to be with the person. This happens for some people more than with others, but often it is in the "being there" that I can offer comfort, a practical hand, and the promise of my presence. These are hard times, but very personally, they are also good times. The reality of our situation stands beside me. I don't have an answer, but I may have an hour or so just to be.

Other Issues

Refusing to take full control

No matter what the role of the coordinator, a key lesson that we have learned is that this person should never take over full responsibility from a family or designated, unpaid circle member.

This means that even when the coordinator is asked, for example, to coordinate the schedule of paid support, the family should always be aware of changes and variations to the schedule. They should certainly be called if last minute arrangements have to be made due to inclement weather, supporter illness, etc. In many cases, the family does know about these incidents simply because they are called in to be with their family member, as a sort of back up. However, a family member should know about all of these changes for several reasons. For one, it gives a clear message to paid supporters that the essential difference between this person's home and a service setting is that a family member is in charge.

Secondly, it is more difficult for a supporter to call in repeatedly to a family member to report car troubles, illness and sundry other reasons for being absent, than it is to another paid person. It is, therefore, another reminder that the supporter role is vital, and that their absence for any but the most serious reasons has an impact on the whole family.

Thirdly, a family member must always have a full picture of the nature of the week that the disabled family member is experiencing. If the family does not hear about the three or four last-minute support changes as they are occurring, they might not understand the impact this must be having upon the supported person themselves. When they are current with changes as they occur, they can begin earlier to look for ways of increasing stability for their family member. It is not that a paid coordinator will not do so, but often for the coordinator if they are able to make an alternate arrangement so that support is provided, they will feel that they have done their job. This is not lack of empathy on the part of the coordinator. I have been in that position myself. However, sometimes back up plans are very difficult to make and take many phone calls to arrange. After all that, it is hard to sit back and say that "things must be done differently!" It may be difficult to additionally place themselves in the shoes of the supported person and figure out that what you have just done is piecemeal at best.

Wolf Wolfensberger in his book, *The future of children with significant impairments: What parents fear and want, and what they and others may be able to do about it,* (2003) lays out clearly the problem with handing over responsibility for your family member to a system of paid services. He says that they often end up under a power equal to that of a parent, but without the love that a parent has for their child. He outlines how, time and again, this is a set up for violence and abuse. He calls this one of the universal laws of violence.

Now handing over full responsibility to a paid coordinator for taking care of support schedules may not seem like handing over responsibility to a paid service system, and maybe violence will not result. However, the true threat lies in the family assumption that *anyone or anything* can fully take over such functions without a controlling role for the family. If the coordinator fully takes it over and does it poorly, will a local service system that offers to coordinate regular support be the next choice? If the local service system has difficulty managing support and offers your family member a "temporary" place in a group home would that become acceptable? If "the family remains in control" is the mantra of the support situation for your family member, these other scenarios will not be contemplated, and this particular risk of violence to your family will be reduced or eliminated.

This is not just the case for the scheduling of support however. It is the same for all of the tasks that might be assigned to a coordinator. The wrong message is given when total responsibility for orientation of new people is given over to current paid people. This is a staffed model where supporters are in charge of "what is best" – even when they have only been around for a year or two in some situations. Family, or a designated person who has demonstrated their caring for and knowledge of the person over time, must remain in control of orientation. They may delegate portions of it to supporters, but they must hold the whole of the orientation, for it is they who must ultimately assess the progress of the individual and their ability to provide good support.

When a coordinator takes over the whole of the recruitment-interviewing-hiring process, once again the individual and their support structure will suffer. Family need to be front and centre of this process as well. Of course, it is helpful and time-saving to ask a coordinator to draft a posting, distribute postings to agreed-upon sites, prepare good interview questions, and draft the family letter of contract offer. But family must find a place to position themselves early in the conversation. For us, once I have determined that the person's availability and basic skills seem to meet the current opening, I pass them along to the family for telephone conversation and to set up the details of the first interview. I may or may not be present for the interview, I assist in setting up the working interview at which I am rarely present. I may return again for part of the orientation process, and when I draft the letter of offer for the family to edit and sign. In many respects, I hold the flow and the pace of the hiring process, but I am not very visible and most supporters are very clear for whom they are working by the end of this process.

My role is most often to hold the whole (the process, the picture, the funding proposal, the principles and philosophy) that the families have already agreed upon. I hold the pace, remind about next steps or practical applications, and often (but not always) invite evaluation. But while I hold, I refuse to do so alone. This is not mine, it does not belong to me. My role is to work alongside or to walk alongside, but it is not to move on alone.

Alone, I have no role to play. I cannot hold the whole on my own. My ideas have no practical side and I am not rooted in the reality of a living family. Alone, I become a threat. I would develop abstract policies, schedules with guidelines, and rules on how things should be done without reality to guide me. . Alone, I would only serve to isolate. I would enter into a world we want to avoid – a world of paid coordinator, paid support, and disabled person at the core, family and friends on the outside. My responsibility is not to go there. The family responsibility is to not to let me.

I remain highly visible to the families, and often barely visible to many others. This duality is also important. Families must know what I am doing, and how I am doing it every step of the way. It is the only way that it can remain theirs. At the same time, our society most often views families – particularly families who have been able to produce members with disabilities – as incompetent. Families are not incompetent. In fact, it is their very competence at a whole new set of tasks during a stressful time in life that have them juggling work loads and expectations that so-called competent families, much less corporate entities, could never hope to accomplish!

This is one of the reasons, however, that it is important for me to reduce my visibility in more public spaces. I do not want others to misunderstand my presence and the hard work that I do as doing instead of the families. Others will presume my competence, they will not do so for the families. They will not see that I have my set of skills and families have theirs, and it is in our work together (and in our common heart) that we accomplish so much. Ways that I reduce my visibility include rarely, if ever, speaking on behalf of Deohaeko Support Network without the co-presence of a family member. We can then each speak from our own experience. In dealing with Supporters, I make sure that the family role is clear, even in the few times when they are not present. I try to write proposal submissions, etc., in such a way that any paid coordinator might be doing the writing, and I refer most often details and questions to family/board members.

A second co-ordinator

Some of the struggles we have encountered has been in finding a role for a second coordinator that works well. We have tried a second coordinator with a similar skill set. We found that we could much more easily find someone with either the family work skills or the administrative-money management skills, but not with both (with the exception of Alison who was with us in this role from 1995-1998. We have tried several coordinators with only administrative kinds of skills, but have not been very successful in retaining them, possibly because the work became very isolated from the rest of what we do and the person ended up being quite on their own and not feeling part of anything. We have no office, no regular meeting times except monthly board meetings, and little down time to just build relations. This is a difficult context for many people to work within, especially since they have most likely built their administrative skills repertoire in an office-type setting. In between second co-ordinators, I would pick up the work until a new person could be found. I'm sure this has led to a reluctance to let go of things on my part.

Identifying some of the struggles

In the task of finding any coordinator for a family group or even for a single family, I think that the following considerations are essential.

It is important that I support the family group, offer advice and direction based on principle and experience, but do not take over. This does not mean that I support anything that comes forward. But it means that I have spent many, many hours in discussion with the group about the common values and principles that will guide us. Then when decisions are considered which go against these, I feel comfortable in pointing this out to the group. It helps that we are committed to a consensus-style of decision-making, and so we work hard to ensure that we understand each other well before we go ahead.

The families and the coordinator must be very clear that the role of the coordinator in the future is not to replace the parent. I will assist in the building of a circle or in the strengthening of family bonds and understanding so that these groups can take on the broader roles that will be required in the future. Stability and commitment lie within family and friends; paid allies can and will be supportive and helpful, but not a governing agent.

Related to this point is the fact that this work can have periods of great intensity, especially since I am working with a group of families. This degree of intensity cannot be sustained. All situations of crisis need to be resolved fairly quickly, at least to the degree that the coordinator resumes a more supportive (rather than direct) role. This frees me up to return to other areas of my role which have been neglected during the crisis or to regain time with my own family. At the same time, this ensures that I do not become the main person in the event of a crisis. On my part-time status, I simply could not manage this role for all families. I can only help families to manage the struggles they are going through. The limits of my time are a curious but effective safeguard to the principle of family control.

In conclusion, I believe that the role of supportive allies are key to the well-being and good support of individuals towards their dreams. However, they have been cast into a supportive role, not as the primary star, and that difference should never be forgotten. There is an Emmy award for best supporting actor, as there is for best actor. They have different roles and different functions, and they are judged, in the end, for their individual performances for the role at hand.

In the same way, as long as coordinators and Supporters are viewed as tools to be used well and wisely in order to work the soil, you can set your sites on a better garden. But when the tools and strategies are more prominent than the flowers and plants themselves, they will only diminish the beauty and the strength that lies about them.