Constructing Social Support
With Vulnerable Citizens:
Promise and Problems

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Formal paid supports for people with disabilities, citizens with severe mental health problems, or the frail elderly have traditionally been provided by either institutional services or community agencies. During the last decade, however, there has been a growing critique of formal services for these vulnerable citizens. Three significant issues have been the focus of these criticisms: the compliance expected of vulnerable citizens within service settings, the segregation of individuals from community life, and the limited social support and relationships that people have in their lives.[1] Much has been written about the marginalization and isolation of people with disabilities and of people who are the poor, frail and elderly. There are many explanations for the lack of relationships and limited social support. It is likely that vulnerability is constructed through all kinds of early experiences, including low expectations, negative attitudes and segregation.[2] Many citizens with disabilities, for example, grow up disconnected from their non-disabled peers and from their communities, often with identities formed by rehabilitation thinking.

There is extensive research on relationships, social networks and social support. Social support has been identified as a critical moderator of stress and provides a key to sustaining human relationships.[3] Social support is also considered as one of the most significant predictors of

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health; people with extensive, rich social networks have greater health and well-being than people who are isolated with limited social networks. Social support is often described as a natural activity of citizens striving to secure relationships and resources they need to participate in community life. Furthermore, it is not just frequency or duration of support, but the quality of support that bears the strongest relationship to positive outcomes.[4]

Because social support of many vulnerable citizens seems to be quite limited, there has been growing interest in "constructing" social support in a way that expands relationships and promotes a sense of community. In this article, I shall outline some experience and research related to constructing social support. In particular, I will look at trends that are occurring with the use of support circles and support clusters, two social support community interventions being used with vulnerable citizens. Finally, I shall suggest a number of preliminary lessons and reflections that emerge from this work, including its relationship to the formal support systems that are so prevalent in the lives of vulnerable citizens

Support Circles

The first documented support circle was established in 1980 by Judith Snow and Marsha Forest to assist Judith in achieving her dreams.[5] This initial support circle was called the 'Joshua Committee' to symbolize breaking down the walls. It served as an inspiration for others who saw this concept as an innovative way to intentionally focus energy and support on the vulnerable person. A support circle is created when a number of people (usually somewhere between 6 and 10) come together to support an individual's voice and dreams, provide advice, advocacy or practical support, help with co-ordination of the person's life, and participate with the person in social activities.[6]

Support circles differ from case management or person centred teams. Meeting informally on a regular basis, support circle primarily consists of family and friends of the supported person. Circle members make a deep

and voluntary commitment to the person. Generally, meetings have a facilitator, usually a circle member, who plays a key role in helping the group keep a focus and develop an agenda. Circles appear to vary widely in their degree of formality, both in terms of the location and the structure of the meetings. While little research has been conducted on support circles, several stories and evaluations attest to the power of the circle in supporting the dreams of the person, enhancing relationships, and providing support for families.[7] Support circles are being utilized by a range of families across Canada who have children with disabilities. They are also increasingly being used by community organizations working with adults with complex support needs.

Support Clusters

The Support Clusters Network of Ontario was originally a three year demonstration project in Kitchener-Waterloo entitled the Support Clusters Project. The original project was designed to explore the effectiveness of working with the social networks of persons with complex disabilities. Unlike support circles, the intervention itself is not aimed directly at helping the vulnerable individual, but rather indirectly by working with the social network or "cluster" around the person. A "support cluster" consists of the family members, friends, *and* professionals who are involved with the vulnerable person. These people, often not connected to one another, are invited by the person or the family to join a cluster.

The central values and principles underlying this network approach include empowerment and partnership. In the research conducted on the Support Clusters Project, social support was increased for twenty families and individuals over a three year period.[8] There were several factors associated with successful support clusters, including: balance in the composition of members between informal and formal support, willingness and capacity to work together, and effective facilitation in achieving the goals. In particular, families were very satisfied with the support clusters intervention. Most families reported a marked increase in their ability to cope with stress. In addition, families reported strengthened relationships with both their informal and formal supporters in the cluster. The role of

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professionals was particularly significant and their participation was valued by families. The Support Clusters Network of Ontario currently educates and supports interested groups and organizations who want to utilize this concept.

Reflections and Emerging Lessons

1. *Constructing social support with vulnerable citizens enhances quality of life, and does not replace the need for formal, paid support.*

Initial evidence suggests that community initiatives such as support circles and support clusters enhance quality of life. Coordination of the vulnerable person's life, and the family, also becomes more possible as members of the person's social network increase their communication and collaboration. However, these kinds of interventions *do not* eliminate the demand for formal, paid support. Citizens with extensive support requirements continue to require formal and informal support. As we are learning, each type of support plays a different role. Community health and social services (formal supports) should address basic needs, such as housing and attendant services, so that informal interventions described here can deal with "higher order" issues, such as relationships and community building.

Some governments are emphasizing that "community" should do more to replace formal paid support. There is no evidence that communities will *just* respond; the process of constructing social support with a vulnerable person is a conscious, time consuming effort. Support circles and clusters should not also be expected to take on all the caregiving functions. Thus, the valuable but limited role that these alternatives play should be recognized. People with disabilities, for example, require accessible transportation, support for employment, and inclusive schooling and higher education. Support circles and clusters will not resolve these system issues that are so important in the lives of all citizens.

2. *Paradoxically, work on constructing social support with vulnerable citizens points to the need for an improved, flexible, and more individualized formal support system.*

Although alternatives such as support circles and support clusters may not take away the need for paid formal support, this work on constructing social support does point to the need for more individualized formal systems. Within support circles, for example, many people learn to dream again and to have goals they would like to achieve in the community. When the formal paid support services people receive are inflexible and tied to "bricks and mortar," vulnerable individuals have few options to act on those dreams. Lessons from these alternatives challenge formal systems to individualize their supports. Formal supports, for example, need to be available when and where the person needs them. In a few instances in Canada, projects have evolved so that individuals and their support circles actually direct support staff and budgets associated with them.[9]

3. *Constructing social support enables families to regain their lives and to relinquish some of the care giving functions.*

Families experience a lot of support when the support networks surrounding themselves and their family member are more fully developed. In many cases, parents have been "captive" in their role as primary caregiver. The support cluster provides a place to express emotions about that experience, and to regain a life. It also provides a context to problem-solve and build a more consistent approach with the vulnerable person. Families feel they no longer carry all the responsibility.

This process of constructing social support not only gives "voice" to the person, then, but also to the family. In some cases, women point to the fact that support is being more shared. While this is a tentative conclusion, it is an interesting one to reflect upon, because informal support requirements generally put more burden on women. The difference here may be the collective nature of the interventions and the

"sense of community" reported by many people involved in these alternatives.

4. *Constructing social support has tensions that influence both process and outcomes.*

Whenever a new paradigm is initiated, some of the tensions associated with the old paradigm fall away. However, new tensions may arise. In the process of constructing social support, there may be tensions between family members and the vulnerable person, or between service providers and informal supporters. There may also be confusion among the group members in regard to the purpose of the group. For example, some members may want to focus on "dealing with the day to day issues" while others may want to focus on advocacy.

In conventional approaches to social support, tensions are usually kept private. Dilemmas experienced by families may not be heard by professionals and vise versa. In support clusters, these tensions are experienced within a community and they are debated and discussed. In some cases, they are not resolved and people agree to live with them. In other situations, the group evolves principles to assist the members to manage the tensions and the paradoxes.[10] Like any community intervention, support clusters and circles will vary in their success. It appears that groups that can manage group process and the resultant tensions produce more positive outcomes. These informal support approaches are typical of interventions where "process really makes a difference."

5. *Constructing social support with vulnerable citizens can act as a starting point for transforming the way our culture might include people and embrace diversity.*

Most calls for change related to disability and aging issues focus on "more services." Although certain segments of the population do require more services, the reality is that our most vulnerable citizens require different services *and* expanded opportunities to be included in

community life. The process of constructing social support enables us to begin to look at "community" and how to build the capacity of communities to include all citizens who are vulnerable. Inclusion means everyone participates; everyone's strengths and gifts are honoured and respected; and everyone is supported to contribute in their own way. Projects that embrace support circles or clusters are based on these kinds of values and beliefs. The "circle" and "cluster" are powerful metaphors for building a society of inclusion and diversity.

These alternatives approaches to constructing social support also raise a compelling point about the nature of acquiring knowledge. Typically, knowledge is seen as individual oriented and expert-based.[11] On the other hand, members of support circles and support clusters experience knowledge as collective and experiential. This different knowledge base is what grounds this work in community, rather than in systems of expertise.

6. *The construction of social support, while attractive to formal agencies, may be best left to grass roots efforts and to the initiative of families and communities.*

Support groups that are led by professionals have been growing in popularity. These groups have been shown to be helpful with information sharing, education and skill development.[12] But, the professional remains in control in a process of disseminates information to citizens or clients. The alternatives described in this paper have a very different feel and clearly have shifted the locus of control away from the professional to a group of citizens. That professionals engaged in the Support Clusters project are able to "leave their professional hats at the door" suggests that there are some professionals who want to engage in more equal relationships with the people they support. The professional reality, much of the time, is that the structures and systems of which they are a part, do not allow them to become involved in relationships in such a manner.

This contradiction can help us resolve whether or not the construction of social support should become a "responsibility" of formal agencies. People who are best at facilitating the construction of social support tend to be involved in grass roots projects or consumer driven organizations, quite distinct from institutional services and formal community agencies. Perhaps this is how it should remain. The idea of social policy and agency structures "taking over" the construction of social support could easily shift the power in such enterprises from citizens toward professionalized service systems.

Where to from here?

Health and social service in Canada face a very uncertain future. Continued cutbacks amidst an aging population creates such a sense of turbulence that conventional paradigms are no longer relevant. In addition, and this may be the most important point, vulnerable citizens themselves are asking for something different. Whether it be consumer/survivors in mental health, self-advocates with developmental disabilities, or frail seniors, citizenship and participation in community life are at the core of their goals and demands.

We are at somewhat of a turning point with these issues. Although the days of warehousing vulnerable citizens *should* be over, there are signs that total segregation is re-emerging in certain areas of the country. We know that formal service systems cannot fully protect people in such times. The thousands of small groups across the country that are constructing social support with vulnerable citizens are teaching us the value of their citizenship and the possibility that families and communities can play a more significant role in safeguarding the quality of life of our fellow citizens. These groups will increasingly demand more individualized and strengthened formal community supports, while expanding the informal networks and community connections of vulnerable citizens and their families.

Does the state have a role to play in constructing social support with vulnerable citizens? To answer this question fully, we need to reflect on two possible policy directions. First, governments can do an enormous amount to *prevent* isolation and vulnerability in the first place. Funding for early family support, educational changes to ensure inclusive education, and funding for more individualized support programs would be a beginning. Second, it is perhaps more controversial to suggest that governments fund communities, families, and disability groups to do this work on their own. If such funding was to occur, it is imperative that it be totally separate from the government funded service system. A parallel has occurred in the mutual aid/self-help area. In some Canadian provinces, governments have been willing to fund a number of mutual aid initiatives, helping to build the capacity of vulnerable citizens to build their own experiential knowledge and confidence.

Should the consumer and family sectors be funded separately? Can communities be funded and supported to enable more vulnerable citizens to construct social support networks? What are some other sources of possible funding beyond the state? Is there a role for churches and other community associations? Is this a more viable way to proceed? These are just some of the policy questions that emerge from this analysis of these very promising community alternatives.

References

1. John McKnight, "Regenerating Community," *Social Policy*, 17(3), 1987: 54-58.

   Steven Rose & B.L. Black, *Advocacy and Empowerment: Mental Health Care in the Community* (Boston: Routledge & Kegan Paul, 1985.)

   John Lord & Peggy Hutchison, "The Process of Personal Empowerment: Implications for Theory and Practice," *Canadian Journal of Community Mental Health*, 12(1), 1993: 5-22.

2. See Ibid. and

Peggy Hutchison, *Making Friends: Developing Relationships Between People With a Disability and Other Members of The Community* (North York, Ontario: Allan Roeher Institute, 1988)

3. Benjamin Gottlieb, "Social Networks and Social Support: An Overview of Research, Practice, and Policy Implications," *Health Education Quarterly*, 12:1, 1985: 6-22.

4. Benjamin Gottlieb, "Support Interventions: A Typology and Agenda for Research," in S.W. Duck (Ed), *Handbook of Personal Relationships*. (New York: John Wiley & Sons, 1988)

Francine Lavoie & Miriam Stewart, "Mutual Aid Groups and Support Groups: The Canadian Context," *Canadian Journal of Community Mental Health*, 14:2, 1995: 5-12.

5. Jack Pierpoint, *From Behind the Piano: The Building of Judith Snow's Unique Circle of Friends*. (Toronto: Toronto: Inclusion Press, 1990)

6. Thomas G. Haring , "Social relationships," in Luanna H. Meyer, Charles C. Peck, C., & Lou Brown (Editors). *Critical Issues in the Lives of People With Severe Handicaps*. (Baltimore: Paul H. Brookes Publishing, 1991), pp 195-217.

Janet Kless, *We Come Bearing Gifts: The Story of Deohaeko Support Network*. (Scarborough, Ontario: PSD consultants, 1996)

7. Deborah Gold, "'We Don't Call it a 'Circle": The Ethos of a Support Group." *Disability and Society,* 9, 1994: 435-452.

John Lord, *A Circle of Circles: Evaluation of Nabors*. (Toronto, Ontario: Neighbours Allied for Better Opportunities in Residential Support, 1996)

Beth Mount, Pat Beeman, & George Ducharme, *What are we learning about support circles?* (Manchester, Conn: Communitas, Inc., 1988)

Pierpoint, *From behind the piano.*

Kless, *We come bearing gifts.*

8. Joanna Ochocka, Don Roth, John Lord, & Eric MacNaughton, *Support Clusters Project: Evaluation Report of a Research Demonstration Project* (Kitchener: Centre for Research & Education in Human Services, 1993)

9. Examples include: Neighbours Allied for Better Opportunities in Residential Support in Toronto, and New Frontiers in London, Ontario.

10. Ochocka, et al., *Support Clusters Project.*

 Charles C. Handy, *The Age of Paradox.* (Boston, Mass: Harvard Business School Press, 1995)

11. Kenneth Gergen (1994). *Realities and relationships: Soundings in social construction.* (Cambridge, Mass: Harvard University Press, 1994)

12. Benjamin Gottlieb, "Support Groups," in Howard Freedman (editor), *Encyclopedia of Mental Health* (Academic Press), in press.