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## **Autonomous Family Groups and Networks:**

### **A Promising Development**

**A Commentary by**

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Families who are raising a child with a disability have a long history of organizing themselves in ways that benefit their children, their family and others. In the 1950s and 1960s, parents founded associations for community living as a way to increase supports and opportunities for their sons and daughters. At the time, these grass root developments played a vital role in providing support to families that were often not available from the public domain. It made sense in the early years that families would seek emotional and practical support from associations for community living. In fact, most of these early associations were strongly influenced by family members and often run by family leaders.

Over the years, associations for community living in most provinces have become large service providers. These services and complex service systems are now run by staff with board members who may or may not be family members of the people they serve. As associations have evolved and grown, many have started to reflect on the role they can play in providing support to families. It is clear that their historical involvement with families has changed dramatically. At the same time, a growing number of autonomous family groups and networks have emerged in several provinces. These groups are separate from the associations for community living and are not attached in any way to the service system. In some ways this is very much like the grass roots gathering of families in the early years.

In some localities, the ‘independent’ and ‘separate voice’ of family groups is causing consternation among those who believe that associations for

community living and other service providers are best positioned to provide support to families. In other areas, autonomous family groups are being welcomed as a new grass roots voice that will enrich and strengthen the work done by community living associations and governments. Leaders in these areas believe that such groups will hold service agencies accountable to provide what is really needed for citizens with disabilities.

This paper will briefly summarize why the expansion of autonomous family groups and networks is a promising development. Furthermore, I will outline how progressive service providers understand this change and are nurturing the development of autonomous family groups and networks.

### **Families and Self-Organizing**

Like all human beings, families have a tendency to self-organize. This means that people seek out possibilities that have meaning and make sense to them. Autonomous family groups began to develop at a time when many associations for community living were evolving into a large service industry. Who would have dreamed thirty or forty years ago that most of our associations would have multi-million dollar budgets, professional staff, and numerous kinds of programs and services!

Autonomous family groups and networks were designed by families to find more intimate space and opportunity for meaningful conversations and support. As this self-organizing expanded, families realized there was a comfort and coherence with being separate from the service world. As well, many families appreciated the freedom to move towards a vision that sees their sons and daughters as having a good life participating and contributing in community.

While initially most members of family groups and networks continued to receive their services from Associations, families realized that the independence of their group gave them power to speak up about things in the service system that they did not like. Families learned they could affect change and have a separate voice to support the things they did like. Family to family support, education, networking, and advocacy have become part and parcel of the autonomous family group.

The development of autonomous family groups and networks in many ways has been a natural evolution in family support in Canada. The original concept of ‘family support’ is rooted in professional practice and was based on the idea that professional ‘interventions’ should be family oriented. This kind of ‘formal’ family support still exists and it is often very helpful to families. Over time, however, we have also learned that there is great value in ‘informal’ family support. It is not surprising, then, that autonomous family groups and networks are family driven. Families determine what is important and valued. This informal family support can take many forms, but what all these groups have in common is a belief that they need to be independent of the service system. This independence also allows for the continued evolution of a citizenship vision for their sons and daughters.

The evolution of autonomous family groups and networks is also linked to the growth of self-help movements in North America over the last thirty years. According to some researchers, self-help is the only area of civic engagement that has been growing.<sup>1</sup> Despite this recent rise in popularity, in many respects the idea of people supporting each other is a return to societies of long ago that found ways to help people with their losses, fears, and suffering. Early pioneers

of self-help groups realized that the power of these groups came from people working on goals that they shared with peers, whether it was women's groups, Alcoholics Anonymous, or mental health recovery. In the area of disability, self-help or grass roots groups play an important role in enabling families to move forward in their lives. Families who are part of autonomous family groups say it is very helpful to share these intimate struggles with other families in a mutually supportive setting.

### **Building on the Resilience of Families**

During the last ten years, research on resilience of families and children has given us amazing insights into the protective factors that enhance human development. The three strongest findings from this research are the need for people to have *caring relationships, high expectations, and opportunities for participation and contribution.*<sup>2</sup> When these factors are present, young people are more likely to grow up with positive outcomes.

Insights from resilience research are consistent with the vision of independent family networks across Canada. In British Columbia and Ontario, groups of families in both provinces have worked together on papers that outline a *Common Vision*. These visions of families are centered in values and principles, including self-determination and community, relationships and networks, and inclusion and participation.<sup>3</sup> I call these new values and principles part of a *New Story*.

Autonomous family groups and networks enable families to have a safe place where they can learn about the *New Story* and participate together to enhance the resilience of their sons and daughters as well as themselves.

It is important to recognize that not all people with disabilities are blessed with resilient families. The reality is that sometimes people are removed from their immediate family and are supported by other caregivers. Some family groups are beginning to reach out to these important family caregivers as legitimate ‘families.’

### **Autonomous Family Groups and Transformation of Service Systems**

Across Canada, governments are trying to transform service systems for people with developmental disabilities. British Columbia is the most advanced in these efforts, while Ontario has committed to changing its service system, as reflected in the Ministry of Community and Social Services document, *Opportunities and Action*. Two things are becoming clear in these transformation efforts; *there is a renewed role for families and separate functions must be created in the transformation of service systems*. Let us look briefly at each of these directions.

A renewed role for families is apparent in the language of documents that are coming from governments and other stakeholders. Person-centred approaches, the building of social networks, and the value of independent facilitation and planning are all part of the *New Story* language. Some governments have even been quite direct in saying that families must play a larger role if we are to achieve the vision of citizenship and inclusion. While an expanded role for families could have negative consequences if this really means government cutbacks, the positive element is the recognition that to expand the resilience of people with disabilities, family participation must be significant.

Several leading coalitions and some provincial governments have stressed that there must be a clear separation of functions in any transformation of service systems. The prevailing systems, where all the functions tend to be embedded with service providers, no longer make sense. Many associations and other service providers not only provide direct support to people, but they also are the main planners, leaders of family groups, leaders of groups for people with disabilities, and may even be the decision-makers about who gets served and how many resources people receive. A clear separation of these functions means less conflict of interest and more likelihood that service providers will be effective with what they were established to do, rather than trying to be ‘all things to all people.’

Proponents of autonomous family groups and networks say that keeping this function separate from service provision makes everyone more effective and honest. In a transformed system, service providers, such as many associations for community living, will continue to provide supports and services. Independent family groups and networks will provide family to family support and advocacy. Independent planning and facilitation will be separate from service provision and from family groups, and be available to families and individuals who want such support.<sup>4</sup>

The transformation of service systems is challenging work. Family leaders have been instrumental in advocating for changes that are consistent with citizenship and with the factors we know contribute to resilience of individuals and families. Building the capacity of autonomous family groups *and* independent planning and facilitation will contribute to genuine transformation.

## **Final Thought on Families and Change**

I recently had an opportunity to spend two full days with the leaders of several progressive service organizations in Ontario, mostly associations for community living. The leaders of all of these organizations are worried about “how to engage families.” We had deep conversations about the role that families play and the absolute importance of family participation in the *New Story* of supports and inclusion. Some of the service organizations were able to show how they have benefited from having an active independent family group in their area. Others described how they were nurturing independent family groups by offering resources and space for meetings. Still others were tentative, but said that the conversations helped them to realize that autonomous family groups make sense and must be nurtured.

Organizations and leaders who resist the development and expansion of autonomous family groups and networks fail to see the natural evolution of family support in the Canadian context. Furthermore, the argument that large associations for community living can re-stimulate a family grassroots movement is totally missing the mark if this means engaging families within current service agencies.

Progressive service organizations will welcome autonomous family groups. They understand that advocacy from families will improve the quality of their supports and services. They value the independent family voice on issues where families and service providers will naturally collaborate. And, most importantly, families themselves benefit from the unencumbered support of other family members.

## End Notes

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- <sup>1</sup> See, for example, R. Putman, *Bowling Alone: The Collapse and Revival of American Community* (New York, NY: Simon & Schuster, 2000). For an overview of research on self-help, see B. White and E. Madara (editors), *America Self-Help Clearinghouse Self-Help Group Sourcebook*, Seventh edition (2002), online [www.mentalhelp.net/self-help/](http://www.mentalhelp.net/self-help/)
- <sup>2</sup> See Bonnie Benard, Using Strength-Based practice to Tap the Resilience of Families, In Dennis Saleebey (editor), *Strengths Perspective in Social Work Practice*, Fourth Edition (Boston: Allyn and Bacon, 2006)
- <sup>3</sup> See, for example, newsletters of the *Common Vision* Group in Ontario. These newsletters are available on the website of Family Alliance Ontario, [www.family-alliance.com](http://www.family-alliance.com) or on the website of the Individualized Funding Coalition for Ontario, [www.individualizedfunding.ca](http://www.individualizedfunding.ca)
- <sup>4</sup> The province of British Columbia has done extensive planning and implementation related to separate functions, particularly the value of independent planning and facilitation. See [www.communitylivingbc.ca](http://www.communitylivingbc.ca)  
In Ontario, the individualized Funding Coalition has done a great deal of strategic thinking about the value of separate functions. See the Coalition web site [www.individualizedfunding.ca](http://www.individualizedfunding.ca) for several papers, including the recent *Signature Paper*.