

Self-determination and Community: Building a Textured Life

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When Andrew Bloomfield was given an opportunity to leave the institution where he had lived for several years, many people assumed that he would move to a group home run by a community agency. His family had other ideas! According to his parents, Andrew's combination of disabilities, abilities, and motivations were so distinctive that planning for his future called for a personal plan for Andrew and individualized funding to provide for the supports he would require. Today, Andrew lives in his own home, is involved in his community, has an active support cluster (a personal support network of family and friends), and participates fully in the planning and implementation of his supports, with the help of facilitated communication. Andrew is experiencing self-determination and community.

It is often assumed that individuals like Andrew, who have complex needs including autism, require a protective life, separate from the choices and community options that other citizens experience. The language of self-determination is almost totally absent from professional discourse about people with significant disabilities. Yet, across North America, families and their professional

allies are discovering that self-determination applies to everyone! Andrew's story reflects this "new paradigm" and the vision of people with disabilities to be able to dream, to make their own choices, take risks, and become citizens and contributors in their communities.

What is meant by self-determination? I believe that an understanding of self-determination begins with embracing the idea that everyone wants to have control over his or her own life. And control is a significant issue for health and well-being! The World Health Organization defines health as the degree of control that citizens have in their lives. When I meet with disability groups, this is the issue they identify most often. People who require disability-related supports say they often have inadequate control over the little things that matter – when to go to bed, what they eat, how their support is provided, who they live with, and where they go in the community. Are these really little things?

Self-determination is also based on the belief that people should not have to give up their rights as citizens in order to receive the supports they require to live their lives. Too often, disability-related supports can only be obtained through agencies, programs, or buildings. Supports based on self-determination principles are controlled by the person and his or her network, and involve the development of individualized plans, supports, and funding. I recently chaired the Ontario Round Table on Individualized Funding, which developed several principles designed to enhance self-determination

and build the capacity of individuals and families to organize and implement their disability-related supports. These principles include;

- Individualized and personal – Planning and support should be directed by self-determined decisions and preferences. Planning is based on in-depth knowledge of the person, and support and funding reflect the unique circumstances of each individual.
- Formal and informal support – Planning and support should include both formal and informal support. Formal support is paid support, with individuals and their networks determining whom they will hire. Informal support includes family, friends, and others in the network of the person.
- Direct and portable – Funding should be dedicated to an individual. The person and/or their designate have control over the funds and choose how the money is to be administered. Funding moves with the person; people with disabilities may live and work where they choose.
- Continuous planning and implementation support – Local planning for individuals and their networks should be unencumbered, and kept separate from service provision. Infrastructures, such as facilitators, are in place to assist individuals and their networks to plan and access their supports.

When these principles are implemented, self-determination has a chance of becoming a reality for the person. Like Andrew's experience, however, many individuals and families are finding that individualized support and self-determination only work when people's lives are embedded in community. Andrew has friends who do things with him, neighbours who care, and a community that enables him to participate in a variety of activities. The context of community makes self-determination become meaningful and rich with relationships and participation, two critical elements of citizenship. When community is part of the vision and focus for individual planning, it enables us to see disability-related supports more broadly. Supports may assist us with the practical aspects of daily living, but they can also assist us in discovering our community and ourselves. One of life's great paradoxes is that being in relationship in community is central to personal growth. For too long, the rigidity of disability supports and the expected compliance associated with them, have left many people with disabilities without relationships, without a life!

By focusing on self-determination and community, we can begin to build a textured life with citizens with disabilities. A recent national research project by Alison Pedlar and her colleagues showed that people's lives have texture when there are authentic relationships, mutuality and respect, and rich participation in the fabric of community life. The study also showed that individualized support and funding contribute significantly to a textured life. As individuals, families, and professionals work toward the new paradigm, they need

to focus on quality of life that includes self-determined supports and community participation. These directions will not be easy to accomplish, but fortunately, there is a growing base of experiences, stories, and research upon which to build a more positive future.

References and Resources

1. Information on how Andrew planned and has realized a good life in the community, with support of family and friends, may be requested from Elizabeth Bloomfield at ebloomfi@uoguelph.ca

2. Copies of the Ontario Round Table Report on Individualized Funding (2000), Linking Individualized Supports and Direct Funding: Making Money Work for People is available for \$5 from the Individualized Funding Coalition of Ontario; 416-447-4348 or email barbara@acl.on.ca

3. The national study on a textured life and individualized supports is available as a book. See Alison Pedlar, Larry Haworth, Peggy Hutchison, Andrew Taylor, & Peter Dunn (1999). A Textured Life: Empowerment and Adults with Developmental Disabilities. Waterloo: Wilfrid Laurier University Press. (Copies available from WLU Press, Wilfrid Laurier University, Waterloo, Ontario, N2L 3C5, 519-884-1970).

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