Building a New Story

Transforming Disability Supports and Policies

Re-Visiting *In Unison*

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For the

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About the Authors

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Introduction

In 1997 the *In Unison: A Canadian Approach to Disability Issues* was released. Prepared by the Federal/Provincial/Territorial Ministers Responsible for Social Services, *In Unison* provides a Canadian vision for people with disabilities based on the principles and values of Citizenship. Figure 1 presents the vision of *In Unison*.

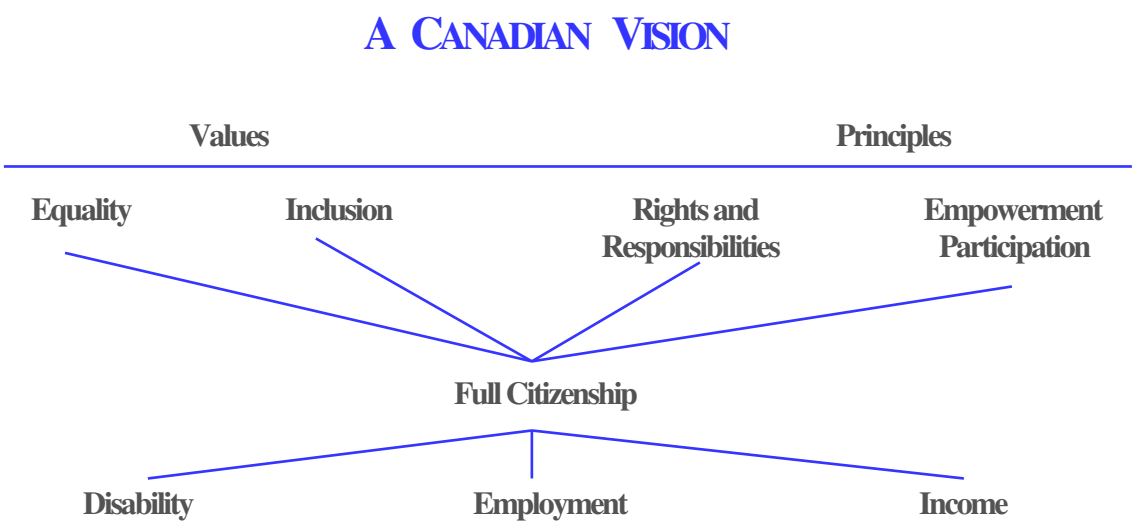


Figure 1 This chart was taken from the *In Unison: An Canadian Approach to Disability Issues*

In Unison has created an important value base for moving disability issues ahead in Canada. The principles of rights and responsibilities, empowerment and participation, and equality and inclusion create a sound framework for thinking about transforming existing policies and programs. However, in implementation across Canada, *In Unison* has proven to be limited in its capacity to create a coherent framework for transforming existing disability systems. If "transformation" of existing disability systems is to be a goal of disability policy, insights from new research and from innovative community initiatives must be taken into account as we re-visit *In Unison*.

As important as *In Unison* has been in the Canadian context, now eight years later there is new knowledge and research that can inform us about how best to build on this important document. By re-visiting *In Unison*, we think it is possible to build a ***New Story*** that can more strategically assist us in further transforming disability supports and policies in across Canada.

Building a New Story

Since the publication of *In Unison*, there has been a growing body of lived experience and research with inclusion, promising innovative projects, and transformation of selected service systems in some provinces.[1] In the year 2005 a ***New Story*** is unfolding in the lives of people with disabilities. Like *In Unison*, the ***New Story*** is grounded in the principles of citizenship. However, we have learned that for citizenship to be meaningful for consumers, families, providers, and policy, it must be explicitly framed around self-determination and community.

> *Self-determination* – the belief that *all* citizens desire to have choice and control in their lives, especially over the disability supports they require. This would include having voice and choice in all things in one's life, including personal development, employment, recreation, and education.

> *Community* – the belief that *all* human beings desire to belong and participate with others in families, neighbourhoods, networks and groups.

Self-determination and community in some ways work against each other. Self-determination focuses on "me" and my choices, dreams and goals. Community focuses on "us" and our sense of partnership, collaboration, and affiliation. In the ***New Story,*** these differences create a healthy tension when support systems are constructed in a way that honours both. After all, true citizenship encompasses both self-determination and community. The challenge with trying to transform current disability systems is that they are built on vastly different assumptions.

In the ***old story***, most systems, services, and policies were constructed to take care of and protect people with disabilities. Recent research, for example, shows that a significant number of group homes across Canada have many of the features of mini-institutions, where people's lives are controlled. *In Unison* clearly makes an important break with that history, but in implementation, *In Unison* can remain in the old story if we cannot use it to figure out how to transform current systems.

In most provinces, health care continues to expand its budget and expenditures. While many provinces are trying desperately to create meaningful health care reform, social service reform has had few proponents and most disability systems have changed little in the last ten years. Many community systems that support people with disabilities are in dire need of change. Two examples will illustrate this point. The call in *In Unison* for more consumer control over disability supports has been implemented very sporadically across the country. Portability of supports and funding, another key objective of *In Unison*, has been implemented in only a couple of Canadian jurisdictions to date.

Despite the inertia of the old story, there are pockets of innovation across Canada that we can now draw on to create new principles and new strategies for transforming current systems. Today, people with disabilities have come a long way in establishing their rightful place as citizens. However, there is still a long way to go. Sound principles, strategies, and the right investments are required to make it happen.

New Building Blocks

The *In Unison* document defines three building blocks for implementing a citizenship agenda. Disability Supports: These refer to a range of goods, services and supports tailored to the individual requirements for daily living and community participation. Employment: Persons with disabilities require access to opportunities for education, training and employment which together comprise the basis for economic independence. Income: Some individuals with disabilities may not be able to support themselves sufficiently or at all, and governments recognize the need for an income safety net.

Many of the goals and policy directions listed under each building block in *In Unison* could be very helpful in setting transformation directions for the new story. For example, under disability supports, one policy direction states that there should be "more consumer control, flexibility, and responsiveness in the provision of disability supports." While important as a direction, for this to become central to the ***New Story***, we need to develop strategic ways for this self-determination goal to become reality.

To build on *In Unison*, we believe that if the goal is to transform systems and supports, new building blocks must address strategic directions that will lead to system change. People with disabilities need to know that there is a foundation of support available to them. These building blocks would include:

→ **Independent Planning and Facilitation** means that individuals and families have access to a facilitator that listens deeply, provides information, and assists with planning, network development, negotiation, and community development. This ongoing planning and facilitation support is based on the strengths, capacities, and self-determination of the person. Research shows that individuals and families benefit from having unencumbered, ongoing facilitation and planning support and that such support provides "value for money."[2] Separating planning from service provision creates a powerful building block for transformation.

→ **Portability of Funds and Supports** means that individuals and families can move supports and support funding that are designed for them to any location or agency within the region, the province, and the country. Portability also gives more leverage to individuals and families for quality assurance. Since portability is based on citizenship rights and contributes to the same opportunities for all, it is an important building block for transformation.

→ **Person-Directed Approaches and Individualized Funding** enable individuals and families to access public funds they require for their disability supports, based on a support plan that is developed by the individual (and family and friends), with the support of a value-based facilitator. Research shows that individualized funding, when accompanied by adequate person-directed infrastructures such as independent planning and facilitation, is more cost-effective than block funding. Expenses are generally cost neutral, but outcomes are better with individualized funding.[3] Since person-directed approaches and individualized funding shift control and responsibility to the vulnerable person, it is a key building block for transformation.

→ **Shared Responsibility and Accountability** means that the person with the disability, as well as other people and organizations involved with the person, are in fact doing what they say they are doing, personally, financially, and collectively. Shared responsibility and accountability are based on the values of self-determination, citizenship, and integrity. In the ***New Story***, accountability functions at several levels, including accountability to the person and their quality of life in community. An explicit trust of individuals and families flows from this approach to shared responsibility. Re-framing responsibility and accountability thus becomes an important building block for transformation.

→ **Economic Conditions that Enable Full Participation** means that policy makers, communities, and corporations take seriously the capacity of citizens with disabilities to contribute to their communities. It also means that systemic change takes place, partly with the implementation of a dynamic labour market strategy for people with disabilities. Economic conditions that foster full participation will enhance the employability of people with disabilities, as well as insure that adequate accommodations are in place, so that everyone can contribute their gifts and strengths to community life.

One important strategy in the implementation of these building blocks is the development of policies and practices that separate key functions in disability systems. As *In Unison* says, this means that access to supports must be separate from eligibility for income support. But, it also means housing and support must be de-linked, and that advocacy, independent planning and facilitation, allocation of individualized funding, and direct services operate as separate functions in the transformed system. Experience in several jurisdictions shows that separating functions enables people to build their own community networks and have more power and choice within the transformed system.

The new building blocks for transformation that we are proposing clearly tilt toward disability support, as opposed to income and employment. **Our experience and analysis strongly suggests that disability supports is the lever for transformation.** Similarly, the disability movement in Canada recently called for new investments in disability supports in its paper *Advancing Citizenship*.[4] While income support and employment strategies are vital, neither

can transform service systems. A labour market strategy without individualized disability supports will not be effective, as we have seen in some jurisdictions in recent years. Similarly, while increasing income supports such as disability pensions do help large numbers of vulnerable people, unless such policies are accompanied by effective disability supports, they only contribute in marginal ways to quality of life and inclusion.

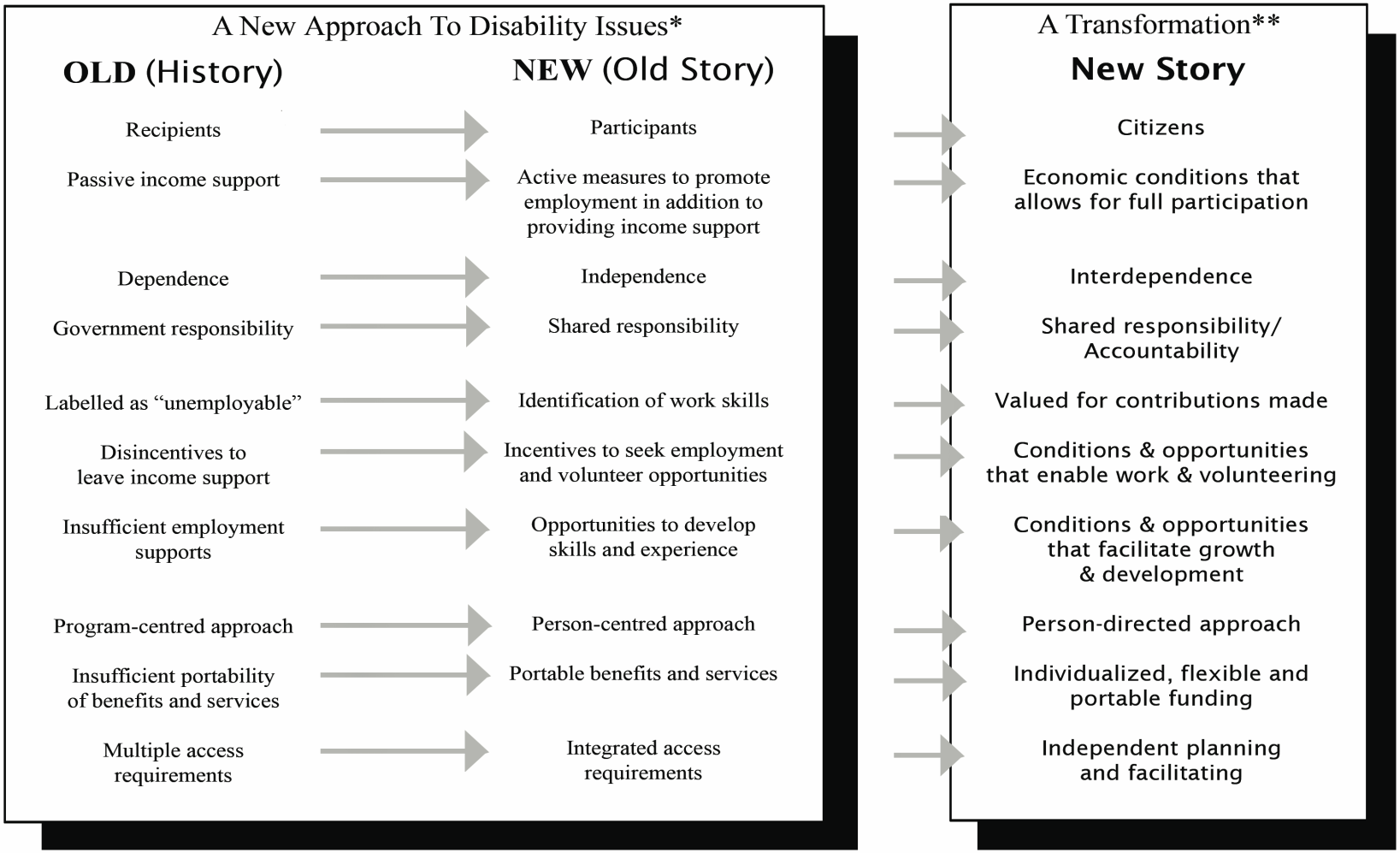
Transformation to a New Story

As we consider how to implement the building blocks for system transformation, it is time for the principles and directions in *In Unison* to be updated. In the following *In Unison* diagram of "A New Approach to Disability Issues," several new directions are listed. We are recommending that each direction be expanded to be more consistent with the ***New Story***. As one example, *In Unison* talks about people in the old approach as "recipients" and in the new approach as "participants." In the ***New Story***, people will be "citizens." With another example, *In Unison* describes the old approach as "program centred" and the new approach as "person-centred." In the ***New Story***, the approach is "person-directed," to be more consistent with the values of self-determination.

The ***New Story*** represents a paradigm shift in language, principles, and practice. As we see in the new diagram below, the ***New Story*** is about transformation of systems and capacity building of people, their networks, and their potential to become citizens and contributing members of society. The ***New Story*** is about valuing the voice and choice of individuals and families and about creating conditions and structures that honour those choices.

REVISITING *IN UNISON: A CANADIAN APPROACH TO DISABILITY ISSUES 1997*

TRANSFORMATION: A COMMUNITY APPROACH TO DISABILITY ISSUES 2005



*Taken from "In Unison: *A Canadian Approach to Disability Issues 1997*"

**Transformation: A Community Approach to Disability Issues

Policy that transforms is different than just good policy. It must be able to deeply reflect the self-determined choices of people with disabilities within a context of community and citizenship. It can only do that by implementing policy based on the ***New Story*** and the new building blocks.

Conclusion

Researchers and policy analysts have long struggled with the role of effective disability policy in Canada. For the last few years, Federal, Provincial, and Territorial jurisdictions have been working together to consider how to create a Canadian approach to disability issues that can have impact on provinces, local delivery systems, and consumers. We hope the ***New Story*** and its implications for re-visiting *In Unison* can be of support to the dialogue about how to create coherent and effective disability policy across Canada.

In this commentary, **we are proposing that "transformation" become a new lens for looking at disability policy and change**. Some have argued that the federal government needs to play a larger role in disability issues and that a significant investment of money will solve many disability issues. While such an investment could definitely be put to good use, it will not be possible to just "buy change." Current disability systems are in such need of reform that any national scheme related to disability must have transformation as a key goal. Like medicare and child care, previous national/provincial agreements that are having a significant impact on the lives of Canadians, a disability agenda based on the ***New Story***, is now positioned to make a difference.

In Unison has been an important national document in the dialogue about how to change the way supports are provided to citizens with disabilities. Our commentary reflects the need to now build on that important document as we consider how to make citizenship and contribution fundamental to the life of every Canadian with a disability.

Endnotes

1 The Individualized Funding Coalition for Ontario has outlined some of this research on its web site. See www.individualizedfunding.ca
Also see, for example, 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.

2 For a summary of individualized planning, support, and funding research, see John Lord and Peggy Hutchison (2003). Individualized Support and Funding: Building Blocks for Capacity Building and Inclusion, Disability and Society, 18:1, 71-86, and the original report on which this work is based called, More Choice and Control for People with Disabilities, available at www.individualizedfunding.ca

3 Tim Stainton and Brian Salisbury (2005). Individualized Funding. Presentation at Policy Forum on Funding Approaches. Toronto: Ministry of Community and Social Services. (visit www.individualizedfunding.ca, under library).

4 The Canadian disability movement has strongly supported the importance of investing in disability supports. A Call to Combat Poverty and Exclusion of Canadians with Disabilities by Investing in Disability Supports is companion paper to Advancing Citizenship, developed by the Council of Canadians with Disabilities (www.ccdonline.ca) and the Canadian Association for Community Living (www.cacl.ca).