

Integrating Everyone’s Expertise Within Self-Directed Supports in Wisconsin

Something happens. A dive into a shallow river results in a spinal cord injury; a car accident leaves the driver with a brain injury; Alzheimer’s disease invades and addles a once keen intellect; a child is born and diagnosed with a label of Down Syndrome ... the list goes on of those day to day occurrences which make disability a natural part of our lives. This paper suggests an approach to integrating the strengths of individuals and families, the communities in which they live, and our formal long-term care systems. Our intent is to begin a dialogue over how we can integrate these strengths in a way that both increase the chances that people will lead fulfilling lives as contributing members of their communities, within an affordable and sustainable system of support and services.

The four quadrant table below illustrates one way to think about the response to an impairment, to a disability:

<p style="text-align: center;"><i>INDIVIDUAL – “I”</i></p> <p style="text-align: center;">Individual Self and Consciousness</p> <p style="text-align: center;">Subjective</p> <p style="text-align: center;">Personal</p> <p style="text-align: center;">Can best be known by self, and for <i>some</i> people by *those who best know and care about the person</p> <p style="text-align: center;">*Family often play that role</p>	<p style="text-align: center;"><i>IMPAIRMENT</i></p> <p style="text-align: center;">Individual Body, Brain & Senses</p> <p style="text-align: center;">Objective</p> <p style="text-align: center;">Can be measured</p> <p style="text-align: center;">Can be diagnosed and treated by “experts” and by the individual</p>
<p style="text-align: center;"><i>COMMUNITY & CULTURE</i> <i>“We”</i></p> <p style="text-align: center;">Community</p> <p style="text-align: center;">Culture</p> <p style="text-align: center;">Values/Beliefs</p> <p style="text-align: center;">Voluntary Associations</p>	<p style="text-align: center;"><i>FORMAL SYSTEMS</i> <i>“It”</i></p> <p style="text-align: center;">Health Care</p> <p style="text-align: center;">Managed Care Organizations</p> <p style="text-align: center;">IRIS</p> <p style="text-align: center;">Professionals</p> <p style="text-align: center;">Public Bureaucracies</p> <p style="text-align: center;">Political System</p>

When there is an “impairment” that results in disability, there are three primary response “systems.” The upper left hand quadrant points out that for some Individuals (the “I”) the impairment is such that they may adjust with little or no help from others, essentially living one’s life in the same manner as anyone else who does not have a disability. A person gradually experiences a decline in their ability to hear, but learns to compensate, to ask others to speak more loudly, to learn to read lips. The majority of people who experience disability grow, adapt and live their lives without entering a long term care system.

And like most people, some individuals with disabilities get by with a little help from their friends. A little help from our friends may be thought of as the Community (the “We”) of the lower left hand quadrant. And friends are only a part of the community. This is the home of our collective values; our culture; our global, societal, tribal, and family belief systems; our communities and the associations we voluntarily join within them. For most people with disabilities the additional support they need to live the life they intend comes from this quadrant.

For individuals who need more substantial support, the Formal Systems (the “It”) of the lower right hand quadrant typically take on more importance. The greater the need for support, or the less support available from the community, the more likely the involvement of the formal systems we have created to respond to particular human needs. When a person is seriously impaired through a spinal cord injury, professionals respond immediately. The medical personnel diagnose and attend to health care issues. The rehabilitation professionals connect with the individual and family. The person and the family typically enter into a world of publicly funded and bureaucratically organized medical, rehabilitation and social services.

All these dimensions are present within the lives of individuals in need of substantial support resulting from a disability. Any truly comprehensive approach will want to touch bases with all three of them, **because they are in fact operating whether we acknowledge them or not.** If we do not deliberately integrate them, we will have a partial and fragmented broken approach to any proposed solution to enable people with disabilities who need support to craft meaningful and fulfilling lives as citizens within our communities.

And do we not today have a partial and fragmented approach to supporting people with disabilities and their families, particularly for those who need a bit more support than they can organize themselves? The Individual, the Community, and the Service Systems argue for dominance. “It is my life,” insists the Individual, “how can I not be most important? Listen to me!”

“With all due respect,” responds the Formal System, “We have developed a complex, comprehensive, expensive system to respond to you and your needs. The medical, rehabilitation, and service systems you rely upon need to be managed efficiently and effectively. Your input is desired and valued, but the ultimate responsibility for managing this system is ours.”

“You have both missed the point,” says the Community, “The richness of life is in community, in its great diversity, in the connections among one another. Both fierce individuality and complex organizations reduce the connections we most value and depend upon.”

For most people who need support that they have not *yet* obtained or may never be able to obtain solely through their own capacities, through their families, and through their communities, the formal systems we have created have *tended* to control and limit peoples’ lives in the process of providing professional assistance. A more integral approach to supporting people with disabilities would acknowledge the critical importance of the formal systems, but also *deliberately* incorporate all three of these perspectives, acknowledging and appreciating what *each* offers.

We expect individuals with disabilities to be able to lead ordinary, typical and extraordinary lives; to be known by others and to know themselves *as the “experts” they are* in how they choose to live their lives, or simply as citizens within our communities. The outcome statements we have created in Wisconsin for

our long-term care system loudly trumpet that expectation. We also want the collective expertise that individuals have in living with a disability to be particularly important in informing and guiding what the Formal Systems create.

We want to work towards building communities and changing our cultures to better understand, respect and value differences amongst us, particularly those differences in appearance, communication and behavior that may accompany an impairment. We want our communities to be welcoming; our schools, universities and technical colleges to be inclusive; employers to be looking for good workers and be willing to adapt the work to enable people with disabilities to have the opportunity to do it well; neighbors to be good neighbors. We are not asking that employers or neighbors provide professional expertise. We are hoping that employers and neighbors see people with disabilities as fellow citizens, not as people who “belong” to a System that will care for them.

We want our formal systems to be powerfully responsive when needed; and to bring professional expertise to diagnosing, treating, and ameliorating the real and potential impact of an impairment within the body, brain or sensory systems. For individuals who need ongoing assistance and personal support where they live and where they spend their time away from home, we want that assistance reliably provided by caring and competent individuals. We want this range of professional and supportive expertise to be available and affordable to all individuals who need it. We do not, however, want medical specialists, educators, disabilities professionals, care managers, administrators, or legislators to act as if they had particular expertise or authority about *where a person calls home, or what educational, vocational, personal, or other life path a person chooses to follow.*

By *deliberately* integrating all of these dimensions we make more conscious, more obvious the appropriate roles of the formal systems for those who need it for whatever combination of reasons at whatever point of time. We renew our understanding of what each individual and family offers, and of the potential that lies within our communities and cultures. We in Wisconsin have not ignored the need to integrate these dimensions. However, a more *deliberate* focus on applying the strengths and gifts of individuals, families and communities is likely to both increase the outcomes we collectively desire, and to do so at less cost to the formal system.

If we were to pay for all the support required by all Wisconsin citizens eligible for long-term care services, we could not afford it, even within our emerging managed long-term care systems and self-directed supports waiver. The reality is that more of the support that people currently receive comes from family and friends than from paid services. For many people that is a good thing. We want to build upon that reality. We do not believe that we have as of yet put the time, energy, and attention into how best to do that, and are suggesting the need to do so now.

For people who are on waiting lists for paid support, or are not able to receive the intensity or the adequacy of support they need from family, friends and community, we want to increase access to the kind of paid support through our formal systems that will strengthen people’s capacity to lead fulfilling lives and be perceived as valued members of our communities. We are not proposing in this paper that we abandon people who need support.

There are an incredible number of learning resources and laboratories in Wisconsin within which we might learn how to integrate the expertise from the three perspectives of the Individual, the Community, and the Formal System. In an era of continuing economic difficulties in Wisconsin and across the country, we have an opportunity today to help shape the future of long-term care in a manner that embraces the challenge of making the most effective use of limited public funding to support individuals to have fulfilling lives within our communities.