Something happens. A dive into a shallow river results in a spinal cord injury; a car accident leaves the driver with a brain injury; a child is born with Down Syndrome … the list goes on of those day to day occurrences which make disability a natural part of our lives.

The four quadrant table below illustrates one way to think about what happens when a disability occurs:

<table>
<thead>
<tr>
<th><strong>INDIVIDUAL</strong></th>
<th><strong>COMMUNITY &amp; CULTURE</strong></th>
<th><strong>FORMAL SYSTEMS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Self and Consciousness</td>
<td>Community</td>
<td>Provider and Health Care Agencies</td>
</tr>
<tr>
<td>Subjective</td>
<td>Culture</td>
<td>Schools</td>
</tr>
<tr>
<td>Personal</td>
<td>Values/Beliefs</td>
<td>Professionals</td>
</tr>
<tr>
<td>Can best be known by self, and for <em>some</em> people by <em>those who best know and care about the person</em></td>
<td>Voluntary Associations</td>
<td>Public Bureaucracies</td>
</tr>
<tr>
<td><em>Family often play that role</em></td>
<td></td>
<td>Political System</td>
</tr>
</tbody>
</table>
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 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 with ordinary assistance from community or public resources.

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 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 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 child is born with Down Syndrome, professionals respond immediately. The medical personnel diagnose and attend to health care issues. The social services professionals connect with the family. The child and the family typically enter into a world of publicly funded and bureaucratically organized medical, educational and social services. This can be a necessary, helpful and appropriate response.

Which of these quadrants is most important?

All of them!

All these dimensions of reality are present. Any truly comprehensive approach would want to touch bases with them, because they are in fact operating in people in any event, and if we do not include them in our analysis, we will have a partial, fragmented, and broken approach to any proposed solution to enable people with disabilities who need support to craft meaningful lives in our communities.

And do we not today have a partial, fragmented, and broken 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, costly system to respond to you and your needs. The medical, education, 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 been able to obtain 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. An integral approach to supporting people with disabilities would deliberately touch all the quadrants, acknowledging and appreciating what each offers.

We want 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. We want the expertise that individuals have in living with a disability to be particularly important in guiding what the systems of the lower right create.

We work towards building communities and changing cultures to better understand respect and value differences amongst us, particularly those differences in appearance, communication and behavior that may accompany a disability. We want our communities to be welcoming; schools 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, or ongoing personal care for people who need extensive support. And, we do not want ordinary citizens to view people with disabilities as “belonging” to the System.

We want our formal systems to be powerfully responsive when needed; and to bring professional expertise to diagnosing, treating, 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, Medicaid 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 integrating all of these response dimensions within an integral framework 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 will also create and renew the understanding of what each individual and family offers, and of the potential that lies within our communities and cultures. By integrating all of these dimensions of reality, we rely on everyone’s expertise, and at this particular juncture in time, we can not afford to continue to ignore the untapped resources available within all of the dimensions of individual and collective human behavior.

6/1/07
Dennis Harkins
A Simpler Way
Madison, WI
dwharks@aol.com