

# Rights and Values in the 21st Century

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## **Sharing the knowledge**

A new century and a new look at the situation facing people with disabilities: it's an appropriate time to consider the rights and realities that have an impact on the people with whom the Wisconsin Coalition for Advocacy (WCA) forms alliances and represents. Depending on your vantage point, you may think of WCA as a source of training, individual advocacy, litigation, or legislative action. But we see the development of *Rights & Reality II* as a unique advocacy strategy which can accomplish outcomes and reach people in ways that none of those approaches will. It is also an effective way to infuse the expertise which WCA has developed over the years into our relationship with people in Wisconsin who could benefit from it.

## **A complex system**

We are hoping that *Rights & Reality II* will shed some light on what has unfortunately become a very complex set of laws, rules, policies, programs, eligibility criteria, spend-down requirements, grievance procedures, prior authorizations, capitation rates, and other hoops that people have to jump through to get on with their lives. Bewilderment and exasperation are not steps toward empowerment - - they take people in the other direction. It's our aim to provide people with disabilities, and their families, friends, and advocates access to clear and understandable information about their services, their rights, and the actions they can take themselves when things aren't working. Twenty-five co-authors of this guide, including WCA staff and many others, have made a massive investment of time and energy to research virtually every nook and cranny of disability rights and services in order to present all this information to you in one place.

It is interesting to think about disability rights and services at the beginning of the new millennium in the context of what has happened in the disability movement up to this point, and in terms of all the issues swirling around us at this particular time. For those of us who live and breathe disability issues every day, the change process seems unbearably slow at times. But in fact, during the 15 years since the original *Rights & Reality* was published, there have been substantial changes both in consciousness and practice which we should not take for granted.

## **Positive developments in the last 15 years**

Wisconsin's total expenditure of community services for people with disabilities has grown dramatically during that time. A number of new early intervention, family support, supported living, supported employment, benefits counseling, community support, and children's wraparound programs have popped up; and most of the people they

serve are satisfied customers. Many people have moved out of State Developmental Disabilities Centers and ICF/MRs, and some people have even beaten the odds and moved out of nursing homes. More students with severe disabilities are included in regular classrooms, and the number of free-standing segregated schools has declined.

### **Many people are discouraged**

Notwithstanding that progress, many people with disabilities and their families in Wisconsin are discouraged right now. There is no end in sight for waiting lists for community services. Prior authorization and other bureaucratic obstacles often get in the way of people obtaining the services to which they are supposedly entitled. Counties and school districts are stretched thin in their efforts to find the resources they need to meet people's basic needs. And our state's longstanding "institutional bias", although diminished, still remains.

### **Values that endure**

Looking to the future, any strategies for positive change must be firmly rooted in progressive values. This is an obvious strand which runs through the accomplishments of the last 15 years. Some of the values which will continue to guide us in the new century have been familiar to us for some time (although our understanding of these ideas continues to evolve):

- Normalization. The concept of enabling people with disabilities to experience life conditions, opportunities, routines, and status as much as possible like those of other citizens continues to be a valid principle.
- Integration, Inclusion & Least Restrictive Environment. "Being there" (i.e., in the community) is not a new idea, but we've enriched the concept. Now it means "community participation" as well as "community presence", and we've learned that "inclusion" suggests a proactive approach by a school or neighborhood, not merely a passive tolerance of the person's presence. We've also moved beyond "Hire the Handicapped" sloganeering approaches to more promising "community building" strategies.
- Independent Living. This concept (and social movement) has also been with us for a while, but it's only in recent years that we have begun to realize that "informal" (or "natural") supports can supplement paid service in important ways to help people achieve the goal of increased independence. We've also become more sophisticated in our strategies for enabling people to own their own homes and obtain satisfying jobs without losing their public benefits.
- Accessibility. People with disabilities have fought for curb cuts and accessible bathrooms for years (and those battles continue). But now "accessibility" also pertains to the right to participate in

programs and activities that other citizens use, and the right to interpreters and technology in order to communicate with other people.

**New concepts** Added to these tried and true values in the disability movement are some newer concepts which already affect our consciousness, and will likely influence the shape of services and supports in the future.

- Self Determination and Consumer-Directed Services. In the past, “consumer choice” generally meant consumers could choose from a government-created menu of provider agency-administered services. In recent years, people have begun to question the “consumer as commodity” assumptions on which such thinking is based. We are now beginning to see a glimpse of a new playing field, in which some people with disabilities and their families will opt out of traditional “case management” and seek services from the yellow pages, their neighborhood, or their extended family, rather than from the roster of county-contracted provider agencies. It’s too soon to say what form this new direction will ultimately take, and whether its “fluid marketplace” reasoning will actually save money, but it has captured many people’s imagination.
- Entitlement with Responsibility. Many thoughtful people in Wisconsin have begun to question the simplistic equation that “our problem is insufficient paid service, so our solution must be entitlement to service”. These people have argued that a total preoccupation with entitlement can result in long term dependency on service (as in “I can’t take the chance of cutting back on my services, even if I don’t need all of them right now”). Such a preoccupation can also undercut the goal of a society in which there is a partnership between government, community, family and the person (i.e., if entitlement to government service is the end-all, then why should anyone else pitch in?). This has led to a new equation in which entitlement to service (certainly a valid idea, particularly for people with severe disabilities) is accompanied by a strong sense of personal responsibility (to do what you can for yourself and your family, to not take more from the public purse than you need, and to expend some effort to make the system and the community stronger for everyone.)
- A New Perspective on “Best Interests”. In various human services decision-making contexts (including the courts), the question of “What’s in the person’s best interests?” has long played a central role. This can have a positive impact, in that it seems preferable than focusing on what’s the cheapest option, what’s most convenient for staff, etc. However, critics have pointed out that “best interest” is sometimes: defined by someone who does not know the person very well; based on stereotypical generalizations about a disability group; reflective of outdated assumptions about who can “make it” in the community; or directly opposite to a

person's stated desires. Consequently, there is increasingly a call for dropping the concept of best interest in certain contexts, or at least counterbalancing it with equal consideration of personal choice.

Whatever the future holds, Rights & Reality II will hopefully enable people to see their way into that future more clearly. Our intention is that this guide will help consumers, family members and advocates become more knowledgeable about their rights, their services, and in some instances their responsibilities. It's important to know well the ground you are standing on now, especially if you are trying to build something new and better on it. And in the new century, just as in the old one, informed consumers, family members, and advocates are the only voices that will bring "paper rights" to life so they can have a real impact on people's lives.