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# Supporting Persons with Developmental Disability — A New Model

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*The way we think about and care for people with developmental disability has changed. Twenty-five years ago, society believed that caregivers always knew what was best for their individual and that he or she must be shielded, even shut away from, the harms that could occur in society. Now, people with disability participate in all aspects of community life. They are educated in local schools, live at home or in their own home, and compete with others in the job market. Caregiving for people with developmental disability is no longer modeled on medicine or stigmatizing labels. Instead, caregivers have become support persons who focus on identifying community resources and making the environment friendlier and safer for persons with disability.*

**A** radical movement over the past 25 years has changed the way we think about and provide support to people with developmental disability (Bradley 2000, Bricher 2000, Swain and French 2000, and Wolfensberger 1972). In the past, society believed that the people who cared for persons with developmental disability knew what was best for them. Professionals protected people with disability from “harms” that could occur in society and took care of all their needs.

For many years, this care was provided in settings that were outside the community, which excluded people with disabilities from the mainstream of community life. They attended special schools, had special recreation programs, lived as adults in special facilities, and rarely had the opportunity to have a job or a career. Often, others controlled their lives. This perception of “caregiving” has changed.

Persons with developmental disabilities now participate in all aspects of society. They live in

homes with their families or in their own homes; they are being educated with their peers in their local schools. Even more, they are employed in the competitive job market, and they are participating as active citizens in their community. The notion of involving people with disabilities in community life has evolved and changed the way that we “care” for those with developmental disabilities.

## Caregiving and Support

The Eldercare organization defines caregiving as “helping someone out, assisting someone, and nurturing them.” Caregiving is helping someone with day-to-day tasks and activities or providing additional care for a family member or friend at home. Such care may be performed by volunteers or one can be hired to provide care to someone who is ill or in need of assistance in the hospital, group home, or in one’s own home. Caregiving varies in intensity and entails a wide range of activities such as assistance with bathing or eating, cooking, cleaning, paying bills, or one-on-one support.

In the disability community, the traditional "caregiver" role has gradually shifted into a role of support. After years of battling for control of their lives and destiny, people with developmental disability do not want to be "taken care of." To them, "care taking" implies inability, helplessness, and need. The "independent living" (or "support") perspective encourages people with disabilities to assert their capabilities personally (Mackelprang and Salsgiver 1996).

People who happen to have a disability seek a life that makes sense for them individually, just as people without disability do; and to achieve this "life," they require support. What is important is that this support be individually tailored to the person and to particular situations. The person who has the disability is the appropriate person to direct that support. In fact, all of us rely on such formal and informal supports throughout our lives.

### **From a Medical Model to a Support Model**

We now understand that a developmental disability is not an illness, and people with developmental disability are not sick. The medical model assumes that the person with a disability is ill and that an intervention will cure or fix his problem. Blaine's case is an example of how untrue this model can be.

Blaine is a fourteen-year-old boy with Aspergers Syndrome who loves acting, plays, and musicals. He can dress himself and do all of his own personal care and daily living activities autonomously. He attends his neighborhood school, where his teacher provides curricular modifications and help as needed. His schoolmates also help him in some activities and have come to accept Blaine for who he is. Blaine is involved in the theatre club and has attended plays at the local community theatre with his classmates. He has a tutor who comes to his home twice a week to work with him on social skills and studying skills.

Blaine is not ill. People with disabilities, whom society assumes are "sick," are expected to fill

this role even when they are perfectly healthy (Mackelprang and Salsgiver 1996). People with developmental disability do not need a cure or to be fixed: they need acceptance, opportunity, and sometimes support or assistance that may exceed that required by those without disability in the same situation. This new perspective describes persons with disabilities as people having talents,

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abilities, capacities, skills, resources, aspirations, potential for growth, and wisdom (Weick et al. 1989). The use of the medical model of disability, though a dominant perspective in the past, has failed to help people with disability participate in, and contribute to, their communities. It excluded people "until they get better" which often meant they were excluded their entire lives.

This changing model is summarized in Figure 1. Whereas the medical model places the problem within the person, the support model places the problem within the environment, community, and society. That is, the support model suggests that if people happen to experience a disability, they may need particular accommodations and assistance to function effectively in the environment. It suggests that such persons may need greater amounts of assistance, more often, and perhaps for a greater duration of time, even indefinitely, to successfully navigate the demands of life. Types of support may include assistance with activities of daily living, technology to communicate, or a personal care attendant to provide twenty-four hour support.

## From Labeling to Individualizing

One of the slogans of the disability rights movement is that "we are people first, before our disability." The medical model of disability focused on the "diagnostic label" often to the exclusion of the whole person and all his or her other characteristics. One's disability thus became life defining, and the label put on one determined all one's possibilities. When the notion of what a person can or cannot do is determined by a label, the focus of planning is on deficiency. The labeling model of disability thus failed to look at and take into account the person's interests, gifts, talents, and potential contributions.

An emphasis on the positive aspects of human capabilities, which is the best stimulus for growth, runs directly counter to prevailing conceptions about problems and deficits (Weick et al. 1989). The support model allows us to look at a person's capacities. In the following vignette, notice how attention to Mike's interests opens doors of opportunity, relationship, community, and contribution.

Mike is a 55 year-old man who lives in a group home. He enjoys going to movies and visiting art museums. He needs support with walking, transportation, and daily living. For years professionals believed that Mike was unable to work a regular job because his measured IQ was less than 60 and he performed poorly on standardized vocational tests. Several years ago, a supported employment agency assisted Mike in getting a job working at the museum gift shop. His coworkers are his primary supporters at work. They and other patrons have come to appreciate Mike's knowledge of and interest in art.

Moving away from a medical model and its accompanying labels points in a more positive direction.

## From Tackling the Problem "in" the Person to Adapting the Environment

Supporting people in changing circumstances means that we must focus on the person first, and then on his or her disability and the environments

### Supporting Persons with Developmental Disabilities

#### Tips to Remember

- A developmental disability is not an illness; it does not need to be cured.
- People are people first, they are not their disability label.
- Adapt the environment or situation instead of changing the person.
- Encourage and respect the person's values, abilities, choices, and decisions.
- Include persons with disabilities in all aspects of their community, in order to build natural supports.

Figure 1. – Tips for Support Personnel

in which he or she lives. Tasks are accomplished in some place, and task expectations make some environments friendlier and safer than others. We need to analyze discrepancies between ability and demand. This analysis will help us develop a variety of supports so that a person with disabilities can successfully participate in his or her environment. Many people with disabilities are marginalized until these environmental analyzes are acted upon. The following example makes this point.

Sarah is a 40-year old woman with cerebral palsy. For many years she was isolated and lonely and rarely left her home. Many people felt that she could not do much because of her physical disabilities. Her brother and some friends helped her learn to advocate for herself and tell her case manager what she wanted to do. Now she gets around in a power chair, takes the bus to the local theater and works in an office using various adaptive computer and communication devices.

Support can take many forms and it is advantageous to propose several alternatives that may work.

Those who use the support model will identify community resources that are part of a person's everyday environment before they turn to or rely on formal social service agencies (Saleebey 1992, p. 43). Support options include

- physical modifications (wheel-chair accessible ramps, grab-bars, lowered cabinets),
- specific training or retraining (cooking skills, laundry skills, job tasks),
- a paid supporter (personal care attendant, direct support professional, caregiver),
- a non-paid person (natural supports: friends, family, shopping center clerk, waitress),
- alternative communication equipment (picture book, communication board, computer),
- adaptive equipment (wheel-chair, shower chair, large print, weighted utensils), and
- modifications of task demands (velcro instead of shoestrings, two-step directions).

### **From Substituted Decision Making to Self-Determination.**

When deficiency defines the person, those who define deficiency hold the power. As our model changes, we can no longer assume that people with disability cannot make their own decisions. Instead, we will discover that they were simply never given the opportunity or experience to do so.

Self-determination is based on principles of freedom: to live a meaningful life in community, to have authority over money, to organize resources in a way that is meaningful and life enhancing, and to take responsibility. Self-determination involves the struggle for control and a voice in the key personal decisions that affect the individual (Herr 1995).

The support model allows a person with a disability to have control over these things and to communicate his or her likes and dislikes. Aaron, a twenty-five-year-old man with autism, demonstrates this point.

As a teenager, Aaron frequently expressed his desire to live on his own after high school. The school and several adult service agencies supported Aaron and his family in developing a transition plan. Aaron also became involved in a self-advocacy organization. As a result he began to talk about the kind of life he wished to live after he graduated. His high school education focused on helping him learn life skills and job skills that would be consistent with his desired lifestyle as an adult.

Now that he is closer to graduation, he is spending half of his school day in working in a print store, which is his career of choice. He plans to continue living at home for a year or so after graduation, and then move into an apartment with Josh, his best friend.

Aaron, like many other people with disabilities may require different types of support to gain this control. He may even need a person who knows him really well to relay his response. Others may require a communication device or need to communicate by using gestures. It is important that we recognize the wants and desires of those with developmental disabilities so that they may increase their self-determination and enhance their quality of life.

### **From Exclusion to Inclusion**

In the support model, an overarching goal is inclusion. In the older model, we emphasized "readiness" which actually had the effect of relegating people with disability to large congregate, isolated facilities that lacked the very opportunities they needed. We have assumed that people with disabilities needed practitioners with specialized skills and training when what they really needed were allies, people who could help them explore opportunities and learn to make their way —

people who would be there when needed. The shift is away from secluded settings, toward inclusion in schools, homes, work-force and the community. The usefulness of this perspective is a key point in the following summary of Jane's experience.

Jane is an 18 year-old girl with Down's Syndrome. She is graduating from a public high school with her friends, many of whom she has known since grade school. She is a "people person" and as a result is well known in her community. She is training to work as a waitress in the local diner. She also plans to continue her education taking some classes at the local community college. The college has a student support center that will help Jane secure tutoring assistance, loan her a tape recorder so she can review classroom lectures, and provide other services she needs to be successful.

In working with the families of people with developmental disabilities, natural resources can include religious organizations, community parks and recreation programs, extended family, and other services to the general public (Russo 1999). To make this shift of perspective successful, we must look at the abilities and attributes that each person brings to his or her community and how we, as a society, can support persons with developmental disability to help them become fully included citizens.

### **Support throughout the Lifespan**

As the American population in general is aging, so are people with developmental disabilities. Persons with developmental disabilities are living longer, which requires those who are providing the support to rethink how support should be provided. Cohen and Nerney (2003) remind those supporting persons with developmental disability that

All people who are elderly, are worthy of respect in the full meaning of the word, and have the capacity and right to flourish, irrespective of the nature or degree of disability. The right to flourish in old age means concretely that individuals who age

with disabilities are entitled to profound respect based on the principles of self-determination.

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Persons with developmental disabilities have the same desires as their peers without disabilities, such as to grow old in their own homes. It is important to adapt the level of support that persons can receive to enable them to continue aging in place. Dave's experience can serve as an example.

Dave is an aging person with mild cerebral palsy. He lives in a group home and works in a sheltered workshop with his friends. He can no longer work five days a week so he has started volunteering at his church two days a week. He has developed diabetes and now is getting support from a home health agency to help him manage his diabetes. Dave's support staffs at home and at work are present when the home health nurse visits Dave so that they, too, can support him in managing his diabetes.

Aging persons with disability may require more assistance with their everyday tasks, or they may require more time or reminders to do certain activities. A person with a developmental disability may experience more rapid changes during the aging process and may require support in areas that weren't necessary before.

For example, an aging person with cerebral palsy who has always been able to feed him or herself may not have the same flexibility as an older person or may develop arthritis. A person with Down's Syndrome may experience signs of

dementia at a much earlier age, than those who develop dementia but do not have a disability. As circumstances change, it is important to look at the level of support that is required at this particular time, to ensure that each person is being supported to live his or her life fully, how and where he or she wants to be.

## Conclusion

A life of opportunity, employment, home, friends, and contribution should be within reach of all people, not just some. Working from a support model helps us know that people with developmental disabilities can experience these things, given the right support. In many parts of the country, people with disability who have traditionally

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been excluded from their communities are in fact purchasing homes, working on a regular basis, participating in their church community, and generally living "ordinary lives" because they have the support and assistance they require. The ultimate question is this: can we let this happen for some people, but not all? The barriers to full inclusion are multiple and include:

- Peoples' belief and attitudes, about the possibility and the "rightness" of including all people.
- Communities that lack the capacity necessary to adequately support all their citizens, including those with disability.
- Disability support systems, including community services, that continue to be structured around available services, rather than individually tailored support.

- Concerns about cost efficiency or funding stream eligibility.
- Human service providers who lack the necessary training and beliefs to provide support to persons with disability, and
- Fear of failure on the part of people with disability and their families.

As a society we have made progress, but we still have far to go. Change needs to occur at multiple levels for progress to continue. Citizens without disabilities need to become more aware of the potential of people with disability by interacting with them in their schools, neighborhoods, and places of business and commerce. Professionals need to continue focusing on each individual's hopes and dreams and help them design supports that will work for them.

In addition, federal and state policymakers and legislators need to continue working together with advocacy and professional groups to create poli-

cies that are user friendly and equitable. Ways to better use the available fiscal and human resources need to be developed so that better lives for people can be supported in cost neutral ways. States need to continue to implement court decisions, such as *Olmstead*, to shift resources away from large facilities toward community supports and service while at the same time maximizing already available generic resources.

Ultimately, shifting from a medical model to a support model is less about funding, money, policies, or programs, and more about coming to appreciate each individual for his or her unique gifts, talents, and contributions. It is about individuals coming to know each other as people and seeing beyond labels to real persons. Only then, will all people be included and each community made a richer place for everyone.

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## Internet Resources

- [www.umkc.edu/ihd](http://www.umkc.edu/ihd). The University of Missouri-Kansas City, Institute for Human Development is a "Center for Excellence in Developmental Disabilities Education, Research and Service."
- [www.moddrc.org](http://www.moddrc.org). An information and referral service offered free of charge to persons with disabilities, their families, professionals, or others seeking

- to locate needed services and obtain materials on a variety of topics related to developmental disabilities and low incidence disabilities.
- [www.ncor.org/](http://www.ncor.org/). National Center on Outcomes Resources
- [www.disabilitymuseum.org](http://www.disabilitymuseum.org). This site promotes "understanding about the historical experience of people with disabilities by recovering, chronicling, and interpreting their stories."
- [www.disabilityinfo.gov/](http://www.disabilityinfo.gov/). The New Freedom Initiative's online resources for people with disabilities"
- <http://www.ncd.gov>. The National Council on Disability
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