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**Abstract**

This paper questions the assumption held by society that the more assistance a person needs the less independence they should be allowed. They argue that the provision of care is based on this assumption. They propose a model which works against this assumed connection. The model describes five different types of commitment that promote well being in the lives of people with disabilities: Anchor / Allies / Assistants / Agendas / Associations. **Keywords: Community Development**



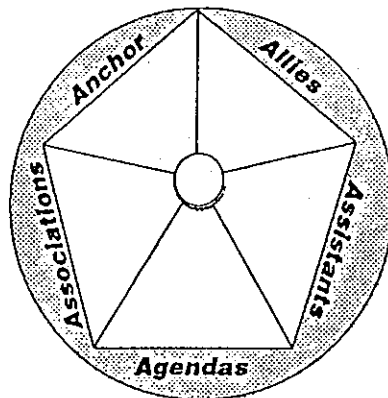
# Commitments That Promote the Well Being of People with Severe Disabilities

John O'Brien & Connie Lyle O'Brien

People with disabilities have gifts and strengths, just as any person does. But people with disabilities are often trapped by the assumption that their ability to live as they choose depends on how close they come to being able to do everything for themselves, without help. Under this assumption, the more help a person needs, the more autonomy the person should reasonably expect to surrender. Policies designed on this assumption set up a continuum of care in which receiving more assistance requires a person to accept more restriction.

Reflection shows that the assumption that independence requires solo performance is false. What is essential to independence is directing one's own life, in relationship with others one chooses, toward goals of one's choosing. It is possible to do this without being able to dress oneself. Those people who are most successful are those most likely to receive or command assistance of many types from many people. Experience shows that people with severe disabilities can live with dignity and autonomy, when other people receive their gifts, invest in them, and assist them.

The diagram, which is expanded on the following page, identifies five different types of commitments that promote well being in the lives of people with disabilities.



- anchor people, who love you and are a source of continuity and strength over time

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# Commitments That Promote the Well-Being of People with Severe Disabilities

## Anchor

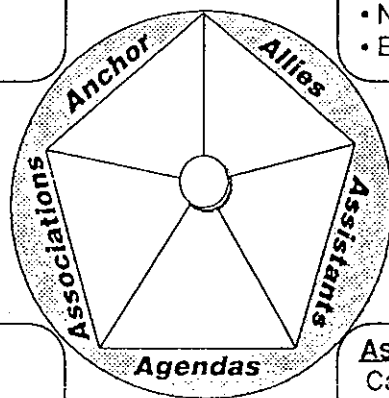
Personal commitment to...

- Be a source of continuity by sharing life over time
- Stand with the person in difficult times
- Grow in knowledge of the person
- Work to create opportunities for the person
- Include the person in life decisions
- Protect the other person

## Allies

Personal relationships in which people...

- Share time & activities
- Share knowledge of person's gifts & challenges
- Share knowledge of community
- Help describe a future worthy of investment
- Make contacts for one another
- Lend practical help
- Negotiate conflicts
- Enjoy one another



## Associations

Formal & informal groups organized...

- To animate civic life by promoting member's interests
- To develop member's skills
- To work for change in policies & practices members see as unjust or disadvantageous

## Assistance

Cash transfer & organized services which make available...

- Money with option of personal control
- Personal assistants
- Links to jobs & learning opportunities
- Devices, adaptations, redesign of activities
- Teaching
- Advice
- Representation

## Agendas

Political action to insure just & effective public policies, e.g....

- Personal assistance services
- Inclusive school classrooms
- Necessary assistance for individual employment
- Individual or cooperative home ownership
- Safe & accessible transportation
- Adequate income without stigma

- allies, who develop personal relationships with you, help you work toward a desirable future, and share knowledge, contacts, time, activities, conflicts and fun with you along the way
- assistance, either voluntary or in the form of money and service supports (such as personal assistance, assistive technology, learning opportunities, advice, and representation)
- associations, formal and informal community groups that organized around members' common interests
- agendas, political action to insure just and effective public policies

When ideas and actions toward a desirable future attract these five commitments a person can move into their future with more assurance and personal power, deal better with setbacks and failures, and be and feel more safe and secure.

Consider the general effects of these commitments for people with disabilities:

- Commitments along all five dimensions empower people, the families, and their communities.
- When a whole dimension of commitment is unavailable to a person, that person is more likely to be physically and emotionally vulnerable.
- A person without anchors and allies is unlikely to feel or act empowered, no matter how much assistance is available.
- People's anchors and allies will be stronger and able to accomplish more if they have many connections to community people and groups rather than being totally dependent on the service system.
- When family members (usually mothers, sisters, or sisters-in-law) are completely or almost completely responsible for assistance, the person needing assistance may come to feel like a burden and choose an undesirable living situation to spare family caretakers.
- A service system whose agenda is aligned with a person's agenda improves the chances that unpaid people will continue to play a part in assisting and supporting the person rather than becoming tired, frustrated and no longer able to provide day to day care and support.
- If assistance is missing or only provided on terms incompatible

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with the person's sense of a desirable future, it takes much more energy for the person to move toward the vision.

- Assistance is most effective when it fits the person's actual requirements as closely as possible. The best way to insure this is to give the person as much direct control of assistance as possible. This means policies that offer a choice of direct control of money to pay for assistance and a choice about the mix of paid and non-paid assistance the person prefers.
- When people lack good assistance, they may be seen as more disabled or less motivated than they are capable of being and their families may be labeled "dysfunctional," "uncaring," or "overprotective."

Jenny Langley is a woman from Georgia who relies on a ventilator to breathe. Until people began to organize themselves around her and her family, she had no alternative but to live in a hospital or a skilled nursing home. Her dream, as she says, was reduce to finding "a nursing home with no bugs." The facing page describes the people and organizations that have joined Jenny to create a more desirable future for her. With them, she has been able to realize a better dream: she lives with her sister and her nieces and is an activist for the rights of people with disabilities and their families.

The final page gives you a place to summarize your image of a desirable future and to identify the people and associations you can call on to clarify, strengthen, and sustain you as you work toward realizing your dreams.

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- To live with my family so I can watch my nieces grow up.
  - To be an advocate & spokesperson for people with disabilities.
  - To continually teach people by being present, involved, & active in my community.
  - To sit in the sun in the back yard.
  - To watch my boyfriend play piano & listen to music.
- Desirable future*

