



PARTNERS
in
POLICYMAKING

Curriculum

PART ONE: HIGHLIGHTS

1993



UNITY

POWER

JUSTICE

INCLUSION

SELF-ADVOCACY

UNDERSTANDING
"WHAT'S POSSIBLE"

INFLUENCING
PUBLIC POLICY



CREATING
A REVOLUTION

OF THOUGHT

AND PRACTICE

FOR
A BETTER
WORLD

*I*n our lives,

We have the opportunity

to make a difference.

We have an opportunity

to influence positive change.

Our tools are:

Our knowledge of what's possible;

Our frustration or sadness or anger at the way
some things are; and our irrepressible commitment
to making life better for all citizens.

We will be challenged

We will (again) be frustrated.

It has been noted that we will not easily achieve
that which has not been achieved...

But if we work hard, we will win!

It's time for self advocates and for advocates

to work together to make

"The world that can be"

more than just words and dreams

the revolution begins with each one of us.

The time for a fully inclusive world is now!

Contents

There are two parts to this curriculum. Part One contains highlights of nine topical areas listed below. The concept highlights may be helpful to Partners with limited reading skills. The highlights do not replace any handouts from presenters in your state.

Part Two is a collection of books, articles, and bibliographies to be copied or purchased as handouts. The collection will be available through the Partners coordinator in your state.

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Each of the nine topics is generally divided into the following sections: Introductory Statements, Competencies, Concept Highlights, Key Readings.

***“Upon graduation,
Partners become
members of the Giraffe
Society because they’re
willing to stick out
their necks.”***

Ed Roberts

**Published: May 20, 1993
Revised January 15, 1995**



1. The History & Future of Services

for people with developmental disabilities*

“Centralized structures are crumbling all across America. But our society is not falling apart. Far from it. People of this country are building America from the bottom up into a stronger, more balanced, more diverse society.”

John Naisbitt, 1982

The history and future are part of a story where the ending has yet to be determined. Each day our actions and our inactions help to write a new chapter.

Chapters yet to come in our lives will talk about our happiness, about our friends, about where we live and about how fulfilling, or how tragic our lives become. What will future historians say about us?

Did we become part of our community?

Did we vote for people who won or lost?

Did we laugh?

According to the United States' Congress (in P.L. 101-136: The Americans with Disabilities Act of 1990):

“Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”

We can't control what has happened to us. What has happened, however, does impact on how we see ourselves, on what our expectations are for ourselves and of the world. It also affects how other people see us and what they expect of us. For all of these reasons, it is important that we understand something about the past and about how it affects us. We need to develop visions of where we want to go in *services* and in *opportunities* with *inclusion*. An understanding of the past will help us to move forward without re-inventing flat tires or repeating yesterday's mistakes.

*Includes the role of parent organizations, of professional associations and of perception.

Ongoing assessment of services and opportunities is essential if we choose to continue living in the present and creating dreams for the future, rather than living in and perpetuating the past.

“In striking contrast to the vigorous and determined leadership of the early pioneers of our movement who pursued their course of action in the face of seemingly unconquerable odds, there is too much readiness in our midst to accept the limitations others set to our work...

...just as our early leaders were not content when officials or agencies assured them in those days that they did ‘the best they could do,’ but demanded the best possible for [people with disabilities], we...must apply the same measuring stick to our own present efforts.”

Presentation entitled: “Are we retarding the retarded?” by Gunnar Dybwad at the Tenth Anniversary Convention of the N.A.R.C. in Minneapolis, MN, October, 1960. Cited in Challenges in Mental Retardation, N.Y.: Columbia University Press, 1964, by G. Dybwad.

COMPETENCIES:

- Participants will be able to describe the history of services for, and perceptions of, people with developmental disabilities.
- Participants will be able to describe significant contributions of the parents' movement.

Concepts:

CONCEPT HIGHLIGHTS:

The past has fostered discrimination against people with disabilities.

The past has fostered the segregation of people with disabilities.

Despite some improvements, discrimination and segregation continue.

How people with disabilities have been treated affects how they have been viewed by others.

We need to look at how services are today and how to make them better.

The parents' movement has played a major role in improving services and opportunities.

Some professional and advocacy organizations and self-advocacy groups have helped to improve services.

We need to "dream big" about the way services should be.

We need to support inclusion, participation, choice, and full citizenship.

We need to work together to make things better.

Services and attitudes have changed dramatically and continue to evolve. Persons with mental retardation have, according to Wolfensberger, been viewed as sick, as subhuman organisms, as a menace, as objects of pity, as burdens of charity, as holy innocents, as developing individuals, and, increasingly, as full citizens. A person is neither a label nor the embodiment of a preconceived notion. Each person is an individual with individual traits, personalities, likes, strengths, needs, dislikes and weaknesses.

Some components of services and change include:

1850s - Educational intent; beginning of centralized services in institutions

1870s - Protect people with disabilities from society—keep people in institutions

1880s - Protect society from people viewed as “different”—put more people in institutions

1900s - Segregation; marriage laws; warehousing continues

1910s - Sterilization; non rehabilitation in institutions

1920s - Exploitation; dehumanization in institutions

1930s - Continued stigmatization; snake pits

1940s - People with disabilities put to death in Germany

1950s - Arc founded; 128,000 people in public institutions; private services are begun in church basements or vacant buildings

1960s - Parent organizations now in 60+ countries; special education in some form in most states; 190,000 people in public institutions; institutional reform begins; President's Committee on Mental Retardation formed; civil rights of people with disabilities come into focus; “normalization” concept introduced

1970s - Decentralization and deinstitutionalization kick into high gear; litigation is prevalent; federal funds are available for residential care (ICFs/MR); “least-restrictive feasible,” the “developmental model,” and “behavior modification” are “in”; self-advocacy begins a gradual emergence; the independent living movement emerges

1980s - Family support and subsidy emerge; early intervention programs are mandated; U.S. Supreme Court rules in favor of group homes in neighborhoods; by 1986, fewer than 100,000 people with developmental disabilities are in public institutions; major strides are made in employment programs; semi-independent apartments are common; institutional closures are increasing; inclusion, choice, and self-advocacy are pursued with vigor.

1990s (partially speculative)- Fewer than 80,000 people with developmental disabilities in public institutions by 1993; the age of institution-free states emerges; privatization continues; families receive credit cards to purchase units of service; institutional census will drop below 60,000 by 1996; new community and family living amendments pass; institutions continue to close; new definition adopted for mental retardation; states adopt supported living; 14th Amendment used to mandate deinstitutionalization in states slow to move toward community and family-based programs; self-advocacy is commonplace and People First is consulted along with the Arc on developing advocacy and self-assertiveness programs for adolescents in regular classrooms; ADA ensures “No Restrictive Environments;” families and people with disabilities are community leaders and public officials setting policy.

2000 - Vision Statement from Partners:

Institutions are closed, paved over and become shopping malls; there are no steps; family support means “whatever it takes;” there are no “isms” (racism, sexism, ageism, handicappism); advancements in attitude result in “what is a disability?”

■ Looking back and looking ahead can appear very confusing. What matters is what happens to one person at a time. What matters is the quality of each person’s life. What matters is what we can do individually and together to make life better and to create more opportunities for inclusion and for full participation.

Attitudes about and perceptions of people with disabilities have gone through significant changes. They should be discussed. They're not finished changing.

George Will

(Detroit News, 6-24-83):

"Even just a generation from now we will, I hope, be mortified by the memory of our complacent acceptance of the social segregation [of people with disabilities]—as mortified as we are today by the memory of racial segregation. We are barely at the beginning of the last great inclusion in American life..."

...THE FULL
INCLUSION OF
CITIZENS WHO
HAPPEN TO HAVE A
DISABILITY.

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- Philosophies and guiding principles have evolved. We each need to understand those which are driving change today.
 - Economics has had a direct impact on what kinds of services have been available and where. "Funding Streams" drive policy and program development. This needs to be understood before redirecting dollars to the community.
 - The size of residential settings preferred by professionals and parents has changed over time. Institutions housing 2500 or more people reduced to 1,000, and later to 250 and to having the capacity for only 100 people. Institutions are being phased-out. Group homes have changed from housing 20 people to housing 6 to housing 4 or fewer. Have you asked people who need supports where they want to live and with whom?
 - The role of parent organizations (particularly Arcs in America) has dramatically influenced services .
 - Professional organizations need dedicated and knowledgeable members including people with disabilities.
 - Laws and litigation have had a dramatic impact on services, especially over the past 22 years. These need to be studied, discussed, and understood. What impact will laws and litigation have on carving out services and supports in the future?
 - Which dreams do we want to support and how? We are still individually and collectively the wheels that drive change (and, as with all wheels, forward momentum requires that the wheels be moving... preferably in the same direction... preferably toward desirable destinations.). LET'S TALK ABOUT OUR TRIP AND WHERE WE WANT TO DRIVE.
 - Finally, so much of what we do is based on what we believe about people and on what we know is possible and on what we know is right.

Key Readings:

Blatt, B., and Kaplan F. (1965). *Christmas in purgatory*, Boston: Allyn and Bacon
A classic essay in words and photographs of legally sanctioned human abuse in state institutions. Extremely graphic and hard hitting.

Summary of existing legislation affecting persons with disabilities. (June, 1992). U.S. Dept. of Education; OSERS 202-205-8241 Provides an overview of existing laws by categories such as education, employment, health, housing, income maintenance, nutrition, rights, social services, transportation, and vocational rehabilitation.

Wolfensberger, W.C. *The origin and nature of our institutional models.* A thorough history of institutions and treatment of the persons who live there. The book is about how institutions create disabilities. Available on loan through the MN Governor's Planning Council on Developmental Disabilities. 300 Centennial Office Bldg, 658 Cedar Street, St. Paul, MN 55155, 612-296-4018.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Toronto: York University, Downsview National Institute on Mental Retardation. A comprehensive theoretical and pragmatic treatment of the normalization principle. Deals with the principle, focuses on its application to specific service areas, and discusses safeguards for the integration of services for people with disabilities into generic services. Available through the MN Governor's Planning Council on Developmental Disabilities.



2. *The History & Future of Self-Advocacy*

***“Find out what is going on and support it or oppose it. Let your voice be heard. If we want rights, we need to exercise rights. In the meantime, do what I’ve been trying to do—
Raise a little consciousness, raise a little hell!”***

Jim Neubacher (Journalist)

There has been some form of organized support or care for people with developmental disabilities for the past 145 years in America. Much of that care was institutions.

For most of that time, people with developmental disabilities have had others speak for them. They have too often been viewed first in terms of their functional limitations, or their perceived limitations. This view has not only lessened their value in the eyes of many, it has decreased their own self-esteem. It has diminished their social role and has reduced their opportunities to exercise full citizenship.

The eternal parent role that society assumed fostered the continued segregation of many people with disabilities. It made discrimination seem like “a shame” but not “an outrage!” If you talk about the treatment of many people with developmental disabilities but, instead, substitute the name of any other minority, the “treatment” seems absurd.

The presence and growing strength of self-advocacy is changing this. People with disabilities began to take control of their lives in the 1970s with the start of the independent living movement. The establishment of People First on January 8, 1974, was a strong part of supporting this change.

The 1990’s will be the decade of self-advocacy. It is extremely important that we understand the reasons for the movement. We either need to support it, be part of it, or get out of its way.

Its time has come.

“... Living like other people in the community is not a privilege to be earned, but a right to be enjoyed, irrespective of ability and need.”

Ann Shearer: *Building community: With people with mental handicaps/their families and friends.*
London: Campaign for People with Mental Handicaps & King Edward's Hospital Fund for London,
King's Fund Publishing Office, 2 St. Andrew's Place, London NW1 4LB, 1986.

COMPETENCIES:

- Participants will be able to describe the history of the self-advocacy and independent living movements.
- Participants will be able to note important ways in which self-advocacy differs from advocacy for others and why the difference is important.

Concepts:

CONCEPT HIGHLIGHTS:

The time has come for people to speak for themselves.

Since 1970 many self-advocacy groups have been formed.

The independent living movement also began in the early 1970s.

Self-advocacy means people are assertive.

Advocates need to learn to support self-advocates.

We need to create visions of the way the world should be.

More self-advocate groups need to be formed.

Groups need to support each other as individuals.

Self-advocacy groups need to discuss their visions and to develop strategies for pursuing their visions.

These efforts are necessary

Between 1970 and 1993 many self-advocacy groups have been formed throughout the United States, Canada, Britain, Australia, Sweden, Denmark and elsewhere. The premise is quite simple: no one else can speak as well on behalf of people with disabilities as people with disabilities can for themselves.

“Speaking out is hard...especially if you think you might lose what you do have. Speaking out is even more difficult when your disability makes it hard to be understood or to communicate verbally. Some people will use that as an excuse to pretend you don’t know what you’re talking about. Don’t let them. When in doubt, listen to your gut and follow your heart. Remember: talk proud, organize, act!”

Medgyesi, V. (1992). *No more B.S.: A realistic survival guide for disability rights activists.* People First of Washington. p. 10.

Wolf Wolfensberger of Syracuse University notes three consequences of people being devalued:

- Devalued people are more apt to be rejected and treated in ways that diminish their dignity and opportunities to develop a positive social role.
- Devaluation sanctions acceptance of poor treatment, social isolation and discrimination against people who are viewed as being “different” in a way considered negative.
- How a person is perceived and treated by others will strongly influence that person’s self-assessment and esteem and, subsequently, how that person thinks and behaves.

-
- Over 200 years ago, this country entitled its citizens to life, liberty, and the pursuit of happiness.
 - Over 200 years ago, the Bill of Rights reaffirmed and explained the rights of **each** individual.
 - Over 100 years ago, the 14th Amendment to the United States Constitution was ratified to fortify the point in law for “equal protection” of rights for all citizens.
 - In 1990, the Americans with Disabilities Act directed the power of these laws and of the 1964 Civil Rights Act specifically toward people with disabilities.
 - A primary value held by the United States (and the United Nations and of many nations of the world) has been an increasing respect for individual human rights, independence, and autonomy.
 - John Dewey, internationally renowned educator, taught that “you learn what you do.” Therefore, if you don’t learn to advocate for yourself, you don’t learn to become more independent.
 - Whether a person is his or her own guardian or not, practice develops capacity. Self-advocacy is essential.
 - Self-advocacy means people speaking for themselves.
 - Self-advocacy is a necessary part of the recognition of people with disabilities as being full citizens, not devalued “second-class” citizens.

Explorations need to follow (in conjunction with select readings and group activities) on:

Starting self-advocacy groups.

Supporting self-advocacy groups.

Creating visions as to how the world should be.

Selecting specific objectives to pursue.

Discussing strategies for pursuing objectives.

Keeping self-advocacy alive through all of the efforts that need to be made in shaping a better future.

■ People with disabilities, regardless of the degree or type of disability, should not be excluded from making decisions about things that affect their lives.

■ The proper place to support self-advocacy is in the nation’s capital, in your state or region, in your county, in your organization, in the service system that you’re personally involved with, in your family, and in your own actions.

“Any real change in the status quo depends on continued creative action to sharpen the conscience of the nation and establish a climate in which even the most recalcitrant elements are forced to admit that change is necessary.”

M.L. King, Jr. in *Strength to Love*

Key Readings:

Brunk, G.L. (1991). *Supporting the growth of the self-advocacy movement: What we can learn from its history and activists*. University of Kansas: Beach Center on Families and Disability, 4138 Haworth Hall, Lawrence, KS 66045. 913-864-7600. Identifies factors that contribute to supporting the growth of self-advocacy. Makes specific recommendations on how to support it further.

Shultz, B., Kennedy, M., and Erevelles, N. (1990). *Materials on self-determination*. Syracuse University, Center on Human Policy, 200 Hungtinton Hall, 2nd. Floor, Syracuse, N.Y. 13244-23401 315-443-3851. Comprised of two parts, both very strong. The first is an overview article, *Self-Advocacy: Speaking for Yourself*, by Michael Kennedy and Patricia Killius. The second is an annotated bibliography on self-determination.

People First of Washington. (1985). *Speaking up and speaking out: An international self-advocacy movement*. University of Oregon, Rehabilitation Research and Training Center, Self-Advocacy Project. Booklet written for people with disabilities who have an interest in organizing or becoming part of a self-advocacy movement. The roles of self-advocates and their advisors are clearly delineated. Ednick Communications, P.O. Box 3612, Portland, OR 97208.

Perske, R. (Ed.). (1989). *Self-determination*. MN: Institute on Community Integration, Univ. of MN Research and Training Center on Community Living, U.S. Dept. of Education's Office of Special Education and Rehabilitation Services (OSERS), and the MN Governor's Planning Council on Developmental Disabilities. Presents 29 recommendations from the 60 conference participants of a national conference on self-determination, more than half of whom are consumers. Strong suggestions and critical information for anyone concerned about people who have disabilities. MN Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg, 658 Cedar Street, St. Paul, MN 55155 612-296-4018.

People First of California. (1984). *Surviving the system: Mental retardation and the retarding environment*. Sacramento: State Council on Developmental Disabilities, 1507 21 st. St., Room 320, Sacramento, CA 95816, 916-322-8481. Important report that is the work of consumers of services for developmental disabilities service systems, not professionals.

Craftwork Communications, Minneapolis. (Producer) (1993). *Shifting patterns* [video tape and booklet] St. Paul, MN: Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg, 658 Cedar St, St. Paul, MN 55155 612-296-4018.

Medgyesi, V. (1992). *No more B.S.: A realistic survival guide for disability rights activists*. People First of Washington, P.O. Box 648, Clarkston, WA 99403. A real self-advocacy guide about real people and real experiences; lessons learned from other groups

3. Inclusive Education



You don't create an inclusive community that accepts and respects individual differences by perpetuating apartheid-based disabilities.

William Arthur Ward, quoted in *Christmas in Purgatory* by Burton Blatt and Fred Kaplan, Human Policy Press, 1974, p.99.

Schools are for learning. We must assure that our children have an opportunity to develop values and responsibilities and to learn the important lessons of life while they are in school. Otherwise, the opportunity may be lost and life will be like a bad oldies record played over and over again.

In 1954, the Federal Court in Brown v. The Board of Education stated that separate is not equal. Now, in 1993,* fewer than 7% of school-aged children with mental retardation are educated in a regular classroom. Forty-four states (including the District of Columbia and Puerto Rico) educated less than 9% of their students with developmental disabilities in regular classrooms.¹ Surely this decade of the Americans with Disabilities Act, which outlaws segregation and discrimination based on disability, is the time to bring this national disgrace to an end.

Just as with institutions, we can understand how separate educational settings began. People with developmental disabilities were virtually denied free public education from the beginning of this century until the 1970s. The first step back to “normality” and to “equal protection” was seen as developing “special schools” which were well equipped for dealing with the “special needs” of “special people.”

Now in the era of community and family living, inclusion, participation, and full citizenship, integration in schools makes sense.

* In spite of P.L. 94-142.

¹ Davis, S. *Report card to the nation on inclusion in education of students with mental retardation.*

“A teacher who makes little or no allowance for individual differences in the classroom is an individual who makes little or no difference in the lives of...students.”

William Arthur Ward, quoted in *Christmas in Purgatory* by Burton Blatt and Fred Kaplan, Human Policy Press, 1974, p.99.

“The only label that counts is the student’s name. The only criterion for inclusion in a classroom is breathing.”

Marsha Forest

COMPETENCIES:

- Participants will be able to describe the reasons for quality inclusive education.
- Participants will be able to outline specific strategies to achieve inclusion and quality education.

Concepts:

Inclusion means that students:

- are integrated into regular classrooms and activities for both education and social opportunities;
- receive an individualized education program with supports enabling them to learn in the regular classroom;
- have the opportunity to participate in school social and extracurricular activities with peers without disabilities; and,
- attend schools in their own neighborhoods and do not attend segregated programs anywhere else...

...Life in the community best occurs when all students of different backgrounds and abilities learn and socialize together in classrooms and other school settings where all have a chance to achieve and receive instruction designed to develop and enhance successful living within the community...

* Separateness (separate-hood).
The Arc U.S., Oct. 1992, p.7. *The Arc Report Card on including children with mental retardation in regular education.* The Arc U.S., 1992, p. 4.

CONCEPT HIGHLIGHTS:

For many years people with disabilities were not allowed to attend school.

"Special" (separate; segregated) schools were developed when public schools wouldn't accept students with disabilities.

People with disabilities are increasingly attending inclusive schools.

Most states are not doing enough to develop more inclusive schools. In fact, some disability groups oppose "inclusion."

Brothers and sisters and neighbors should be able to attend the same neighborhood schools together.

You don't help to support an inclusive world by separating people in different schools.

Integrated schools are better for students with disabilities and help to promote friendships.

Individualization means: where will the student be taught, what will the student learn, who can teach, and how can adaptations be made.

Circles of friends help everyone.

Change the methods, change the technology, change the environment.

Questions to ask about a school's policies, practices, and educational opportunities:

1. Does the school administration emphasize the preparation of **all students** to live and work in the community?
2. Does the school leadership promote the inclusion of **all students** through written materials, presentations, conferences, flexible scheduling, building accessibility?
3. Do all school personnel receive annual in-service training on the values and implementation techniques of inclusive education?
4. Does the student attend the same school that would be attended if the student did not have a disability?
5. Does the student use the same transportation as students without disabilities?
6. Is the student's school day (length of day, time of arrival and departure) the same as the school day for students without disabilities?
7. Does the student participate in extracurricular activities with students without disabilities?
8. How much academic/instructional time does the student spend with students without disabilities?
9. Are curriculum materials age-appropriate?
10. Are curriculum materials used by students without disabilities of the same chronological age?
11. Do supports match the student's strengths, needs, preferences, interests?
12. Do curricular and extracurricular activities involve mutual interaction with students without disabilities?
13. Are educational objectives based on a comprehensive assessment of the student's strengths?

People genuinely interested in integrated education need to review:

- The benefits to students with disabilities such as having more role models, a feeling of connectedness to the community and to non-disabled peers, and an opportunity to develop relationships with more people from his or her neighborhood who attend the local school.
- The benefits to the students already attending the neighborhood school, the opportunity to develop a relationship to a person who may be different in some ways, the chance to better understand the range of human differences, an opportunity perhaps to help someone in a truly interdependent world.
- The difference between learning from your teacher and learning from your peers (positive role model carry-over, incidental learning, deductive learning, peer support, consensual validation of behaviors and positive skills, having something in common with a non-disabled person which can lead to friendship and bonding). A teacher may be wonderful, but there are many more opportunities for learning than are represented merely by the student-teacher relationship.
- Read *The Report Card to the Nation*, particularly as it relates to your state.
- Strategies for opening the doors for brothers, sisters and neighbors to all go to the same classrooms .
- The potential value of a Circle of Friends.
- The role technology can play in supporting a person in an inclusive school.
- The relationship of *Brown vs. the Board of Education* to the ADA.

Key Readings:

Feature issue on integrated education. ***Impact***. (1988). Institute on Community Integration, University of Minnesota, 1 (2). 109 Pattee Hall, 150 Pillsbury Drive, S.E., Minneapolis, MN 55455. Includes overview, historical perspective, philosophical foundations, information on changing systems, strategies and resources.

Schaffner, C. B. and Buswell, B. E. (1992). ***Connecting students: A guide to thoughtful friendship facilitation for educators and families***. PEAK Parent Center, Integration Program, 6055 Lehman Drive, Suite 101, Colorado Springs, CO 80918, 719-531-9400.

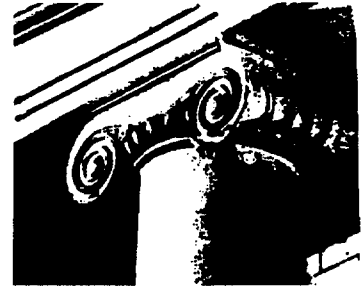
Schaffner, C. B. and Buswell, B. E. ***Opening doors: Strategies for including all students in regular education***. Contains practical “how-to’s” for including and supporting all students in regular classes. Available from PEAK Parent Center.

Schaffner, C. B. and Buswell, B. E. ***Discover the possibilities: A curriculum for teaching parents about integration***. A guide for parents and educators to see the values of integration and ways to achieve it. A set of transparencies that complement the curriculum is also available from PEAK Parent Center.

Buswell, B. E. ***Friendship-building strategies***. A workshop that helps families, teachers, advocates and support staff to explore ways to assist children with disabilities in building friendships. Includes a workshop script, training objectives, set of 9 transparencies, camera-ready set of originals and bibliography. Available from PEAK Parent Center.

Inclusion Press. A small independent press that produces readable user-friendly books and other resources. Contact for a recent list of readings. 24 Thome Crescent., Toronto, Ontario M6H2S5, 416-658-5363.

4. Supported, Competitive Employment



The Rehabilitation Act now recognizes that disability is a natural part of the human experience and “in no way diminishes the right” of individuals to, live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

The committee intends that references to the terms “inclusion and integration” reinforce the principle that individuals with disabilities, regardless of the nature, type, or severity of disability, should have the same opportunity as their nondisabled peers to experience and enjoy working, leisure time activities, and other like experiences in our society.

For so many people, much of their identity and much of their opportunity for relating to others is tied directly to their work. When you meet someone, you ask, “What’s your name? What do you do?”

Work gives us a context.

It gives us a purpose.

It gives us a reason to be with other people and to work with them to achieve something.

Work gives us satisfaction as having performed it and sometimes even pride.

In many jobs, there is a sense by workers that they are doing something that needs to be done in this world and this makes them a part of it.

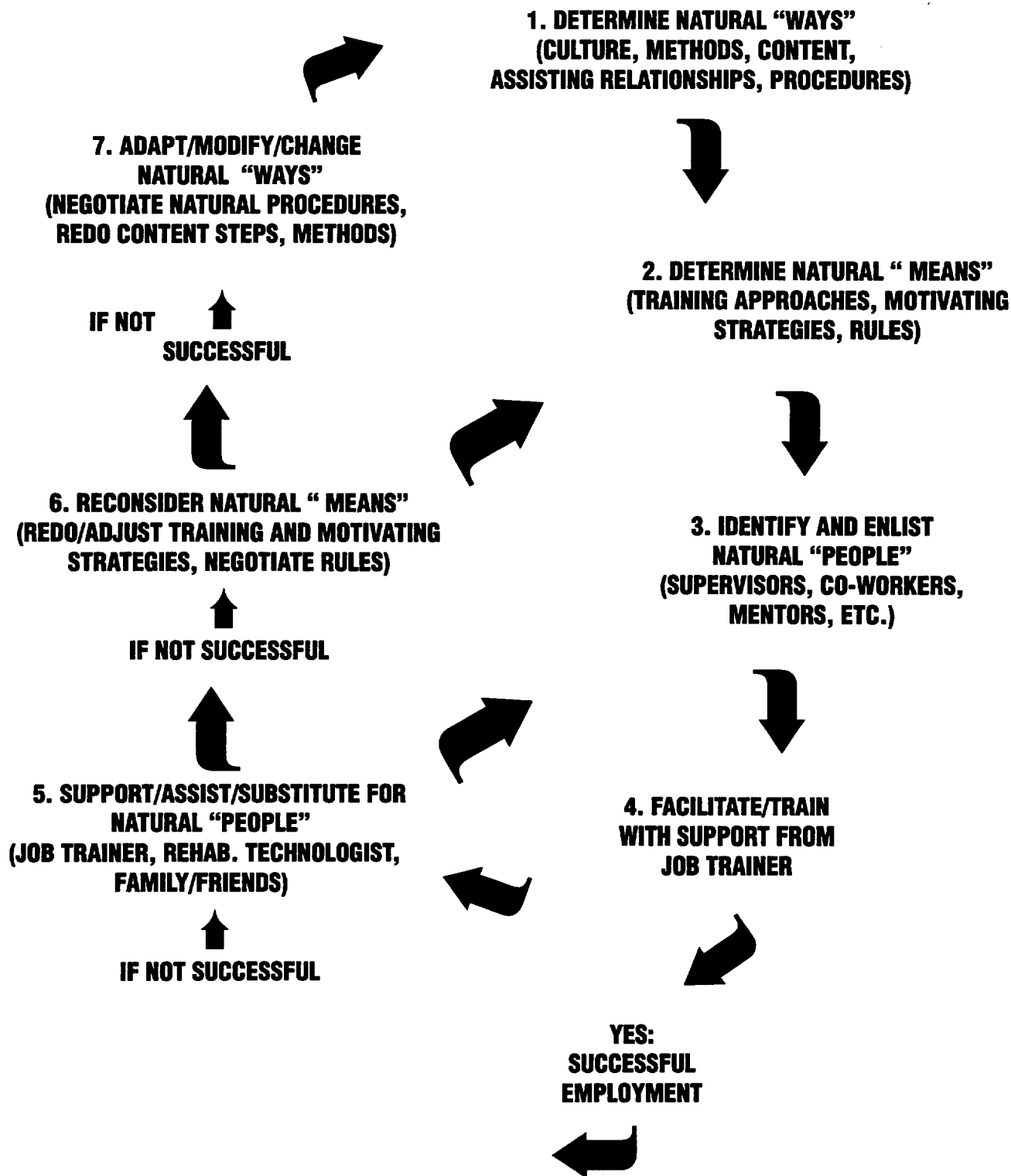
To not have work can be to no longer be connected...

To no longer know what we’re a part of and to no longer have an identity.

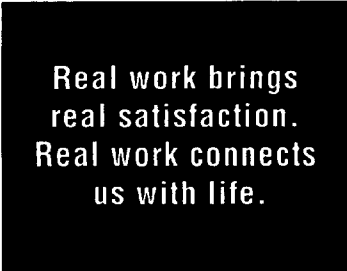

In thinking about “supported work,” we need to first look at what “work” is and what working means to each of us, and then to look at who has been denied this opportunity and to ask “why?”

Senate Report 102-357,
The Rehabilitation Act
Amendments of 1992
P.L.102-569.

SEVEN PHASE SEQUENCE FOR BALANCING NATURAL SUPPORTS AND INDIVIDUALS NEEDS



SOURCE: Marc Gold & Associates



Real work brings
real satisfaction.
Real work connects
us with life.

Once we understand “why,” we can work to change it.

Once we know what support someone needs to achieve a task... and once we connect that person to a job... it’s amazing to see what it does to the person.

Work is magic.

It’s important that we understand the relationship between human potential, work, self-esteem, happiness, and being valued by others.

COMPETENCY:

- Participants will be able to describe the importance of supported, competitive employment opportunities.

Concepts:

CONCEPT HIGHLIGHTS:

Employment gives workers self-esteem.

Employment can contribute to productivity and happiness.

The unemployment rate for people with disabilities is 72%; of those, 67% want to work.

Only one in every four of all Americans with disabilities has a full-time job.

Employers generally feel that people with disabilities are good employees.

Workers with disabilities may be more reliable on the job than many workers without disabilities.

Supported employment is a way to help people with more severe disabilities get and maintain a job.

Segregated work settings are being phased-out.

Productive work helps people achieve independence.

Employment promotes empowerment and choice.

Employment increases the number of Americans paying taxes.

“Being denied a job because you are not employable is not much different than being denied a job because of discrimination. The point is, you don’t have a job!”

Hubert H. Humphrey 6/2/66

“If we were half as clever in providing jobs as we are in denying them, we could have whipped this whole problem of discrimination in employment a long time ago.”

Hubert H. Humphrey 10/9/67

According to the 1991 Lou Harris Poll, more than 8 million Americans with disabilities, ages 16-64, want to work but cannot find employment. Only one of every four people with disabilities who work, have a full-time job. Forty percent of people with disabilities over 16 did not finish high school. Americans with disabilities are much more likely to be poor and much less likely to be able to find work than most Americans. Harris concluded that lack of employment was a major indication of what it means to have a disability in America.

Another Harris Poll was conducted to ask business managers about the employment and lack of employment among people with disabilities. The poll reported on a feeling among employers that people with disabilities are good employees, that the cost of job accommodation is not burdensome, and that there are not enough “qualified” people with disabilities to hire.

A telephone survey, conducted by Lou Harris and Associates in 1991, presented these key results:

■ 98% believe that everyone, including people with disabilities, should have an equal opportunity to participate in American society;

■ 90% said that society will benefit from having people with disabilities become more productive and contributing to the economy rather than dependent upon public financial assistance;

-
- 82% see putting people with disabilities to work as a boost to the nation rather than a threat to the jobs of people without disabilities;
 - the majority support the increased employment of people with disabilities.

Hopkins, K.R. (1991). Willing to act. [Summary of Louis Harris and Associates survey findings on public attitudes toward people with disabilities].

SUPPORTED EMPLOYMENT is a type of employment designed for a person who may previously have been considered too severely disabled to work. It enables persons with severe disabilities to work at typical jobs in the community by providing the specialized training and support services they need to be successfully employed.

As far back as 1985 (*Psychology Today*, March 1985), Paul Wehman was reported to have placed 145 people with disabilities into competitive employment. They were working for at least minimum wage with workers without disabilities (with no subsidized wage). They had been on the job for an average of 15-1/2 months. Their medium I.Q. was 48. The issue, my friends, is ability [not labels; not I.Q.s].

The challenge is to our creativity and to our capacity to be competent teachers to help people to hold competitive jobs.

The President's Committee on Employment of People with Disabilities notes:

When it comes to the subject of employment, people with disabilities represent the widest possible range of interest and abilities. As a result, the widest range of program options must be available to our communities as they strive to meet the employment needs of all their citizens with disabilities.

Twenty years ago Ron Conley reported on the economic advantage of helping people to become more independent. More recently, it's been suggested that in a lifetime, a worker with mental retardation can earn more than \$10 for each dollar spent on training (McLeod, B. Real Work for Real Pay, *Psychology Today*, March 1985).

Features of Supported Employment Include:

- Paid employment.
- Integration with workers without disabilities.
- Ongoing support.
- Focus on workers with severe disabilities.

Factors that make supported employment successful include:

- An individual assessment process.
- An individualized job match.
- Individualized training and adaptation at the work site.
- Individualized supports.
- Follow-along and ongoing supports.

Approaches to supported employment include:

■ **Individual placements** - In this approach, one individual is placed in a job in a community business or industry. Training is provided on the job site in job skills and work related behaviors, including social skills, by a job coach or employment training specialist. After performance reaches the employer's standards, training and on site support is gradually faded to a stable minimum. Intervention is increased if needed. Periodic communication with the employee and employer is ongoing.

■ **Natural Supports** - See chart on page 22

ALTERNATIVE APPROACH TO TRADITIONAL JOB PLACEMENT:

Comparison of a "Traditional" Approach and a Consumer Empowerment Approach to Supported Employment

Issues	"Traditional" Human Services Approach	Consumer Empowerment Approach
What is the problem?	Individual's lack of job skills or motivation	Discrimination Lack of supports
Where is the problem?	In the individual or in his or her family	In the environment (employers, service system, etc.)
What is the solution?	Evaluate, prescribe, prepare for special services	Obtain supports as needed to facilitate career movement
Who is in charge?	Professionals in the service system	Individuals with help from support providers

(Kregel, J., in *Consumer advocacy and supported employment: A vision for the future*. (1992). Brooke, K., Barcus, M., and Inge, K. (Eds.) Virginia Commonwealth University, Rehabilitation Research and Training Center).

Only that day dawns
to which
we are awake.
There is more day
to dawn.
The sun is but a
morning star.

H. D. Thoreau

Michael Shafer notes (1989):

There is little doubt that the development of supported employment and its authorization by the federal government represents a basic, fundamental shift in the social policy of this country. Similar to the deinstitutionalization movement of the 1960s and the public special education movement of the 1970s, the supported employment movement of the 1980s is producing widespread philosophical and structural changes in the manner in which rehabilitation services are provided...

Philosophically, the importance of productive work as a means of achieving social equality and financial independence has now been recognized to apply to individuals with severe [disabilities]...

...Supported employment is based upon the philosophy... that all individuals are capable of engaging in meaningful and remunerative vocation activity... that individuals with severe disabilities should be provided only with rehabilitative services that support the opportunity to engage in meaningful and socially valued vocational activity... and that employment opportunities should be made available only in integrated settings.

We need to come back into focus on what work is and what it means for each of us. We need to look again at what the absence of work would mean for us or for another person. This is a remarkable era of inclusion and of breaking down some of the last great walls of segregation against people with disabilities.

Employment, choice, esteem, and empowerment are among the great victories that we're just beginning to be able to celebrate together.

Key Readings:

Bibliography on supported employment (1992/draft) Eugene, Oregon: University of Oregon, The Employment Network Specialized Training Program. Eugene, OR 97403, 503-346-53. 192 pages of bibliography, subdivided into over 50 separate topic areas. Amazing.

McLoughlin, C., Bradley-Garner, J., and Callahan, M. (Eds.). (1987). ***Getting employed, staying employed: Job development and training for persons with severe handicaps.*** Baltimore: Paul Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. A "How-To" manual filled with strategies.

Nisbet, J. (Ed.) (1992). ***Natural supports in school, at work, and in the community for people with severe disabilities.*** Baltimore: Paul Brookes Publishing Co. An easy to read description of how to avoid paid supports by fostering friendships.

Wehman, P. (1992). ***Life beyond the classroom: Transition strategies for young people with disabilities.*** Baltimore: Paul Brookes Publishing Co. Guide to planning, designing and implementing successful transition programs for students with disabilities.

5. Whole Life Planning



“There are incredible changes in the child who has friends. The friends Tom makes now will change attitudes 20 years from now.”

Cindy Diger, Parent Case Manager, in: *Shaping case management in Minnesota: In theory, reality, and practice* (1991).
MN Governor’s Planning Council on Developmental Disabilities

This way of looking at people, and at their lives is variously referred to as “Whole Life Planning”, “Lifestyle Planning,” as “Personal Futures Planning,” and as “Functional Life Planning.”

It’s a way of looking at people in terms of their whole life...looking at the whole person.

None of us is just an arm or just a label or just an attitude or just what we were yesterday.

We each have wants, needs, strengths, areas where we need support, likes, dislikes, esteem, a past, and a future.

Hopefully we have people who care about us.

Who respect us.

Who like us...and who can help us grow and expand and experience the world more fully...and who can help us look at the future and at ways to make it even better.

This whole person/ whole life planning process is a way of seeing people based on strengths and on potentials.

It is a process that must be understood by families, by advocates, by self-advocates, by case managers and by others who are genuinely interested in improving people’s lives.

To be a living, breathing human being is so much more than being a label with parts that need fixing. Each person and each life is like a perfect flower waiting for the right elements to bring out its full beauty.

COMPETENCY:

- Participants will be able to describe the importance of whole life planning for people with developmental disabilities.

The future is a precious gift for each of us. The package is entirely wrapped and it's hard to guess what's inside.

If we're fortunate, it was at least partially picked-out, or will be, by people who not only know what they think we need (a new pair of socks or to learn to evacuate the house when the fire alarm rings), but know what we want... (to be able to go to a basketball game, to have a job, to have a friend). It's those little gifts from people who really know what we like and want that make us smile the most... These are the things that make gift-giving meaningful (i.e., full of meaning for us) and something to look forward to, rather than something to be dreaded. Wouldn't it be nice if individual program planning processes were always things to look forward to where future gifts were planned and wrapped?

Concepts:

W. Edwards Deming said: "People are born with intrinsic motivation, self-esteem, dignity, curiosity to learn, joy in learning. The forces of destruction begin with the toddlers... (*The fifth discipline: The art and practice of the learning organization*, by Peter Senge. 1990). Actually, the forces for many start even earlier. Preventable causes of developmental disabilities as well as some genetic causes may begin to have an impact almost at the time of conception. The quality of prenatal care and the nurturing or diminishing nature of the environments we are born into play a role. Years ago, Roger Hurley wrote of the too common relationship between poverty and mental retardation, and still how many people have no health care and have inadequate nutrition and don't have prenatal and post-natal care. Was it Rosemary Dybwad who said; "Why does early intervention always come too late!" For people with disabilities, positive opportunities have often never been extended. Chances to experience positive feelings through a sense of being connected and being viewed in a positive, powerful and unique way are not always common for people with functional limitations.

When people have been seen first in terms of a disability or a difference (see *The Invisible Man* by Ralph Ellison), they have often been kept away from the variety of stimulation and life experiences which foster growth. Life in institutions and nursing homes has greatly curtailed the opportunity to learn and to develop independence for many people.

CONCEPT HIGHLIGHTS:

"Whole Life Planning" is a way of looking at people in terms of their whole life.

It looks at the whole person and at capacity building.

It's also referred to as personal futures planning, and lifestyle planning and functional life planning.

None of us is just a label.

We all have strengths, wants, needs, likes and dislikes.

Families and professionals and advocates need to understand whole life planning.

Seeing a person in terms of their strengths and potential can help to develop that potential.

What are your dreams?
What are your nightmares?
Who is committed to assisting you? Take off the "filters" of disability.

Having friends and being happy and doing things that you want to do can help to expand your life.

Life books are important.

Circles of friends are important.

Participation and choice and self-esteem are important.

We're each capable of growing and developing more ability and more independence.

■ Awkward and unusual behaviors have been learned through an institutional experience. Some people can't communicate verbally and we have to be willing to take the time to get to know them to start to understand what they're saying.

■ To have friends... to develop and maintain positive relationships... to have positive role models and opportunities to experience new things and to participate in the world; these are all important goals for each of us regardless of the nature of our abilities or apparent limitations.

■ When you meet a person, that person is in part the product of a lifetime of positive and negative experiences. Get to know a person well. Don't make an early judgment. Be sensitive to feelings.

■ Think about the importance of relationships.

■ Understand the value of "Lifebooks" *and "life videos"*** for people as they move and as each person's life evolves.

■ Learn about Circles of Friends.

■ Learn about self-esteem and the value of participation and choice and opportunities.

■ Look at people's capacities; look at people's whole lives, and look at capability building.

* Lifebooks are photo albums and scrap books that contain photos and memorabilia from places you have lived and things you have done. Regardless of any functional limitations, this gives positive experience and a sense of continuity to the person whose book it is. It also gives them depth in the eyes of the people just now meeting them.

** Life videos are videotaped versions of the same thing. They can be made at any time.

Key Readings:

The Arc. (1991). *A family handbook on future planning*. A handbook to help parents understand and organize a future plan for a son or daughter with mental retardation. Includes information on wills, government benefits, support services, financial arrangements, guardianship, working with an attorney and other important areas. Forms, checklists and outlines, along with completed examples, help parents estimate their child's needs, and then organize their estate to help meet those needs. 133 pgs. Arc/US, 500E. Border Street, S-300, P.O. Box 300649, Arlington, TX 78010, 817-261-6003.

Mount, B. (1990). *Making futures happen: A manual for facilitators of personal futures planning*. Produced by Kay Zwernik. Focuses on capacities of effective facilitators: basic values and assumptions, creating conditions for change, managing the learning process, running an effective meeting, and renewing and maintaining commitment over time. Looks at the change process, at capacity building and at planning together. This is a very worthwhile resource. MN Governor's Planning Council on Developmental Disabilities.

Mount, B. and Zwernik, K. (1988). *It's never too early/it's never too late*. St. Paul: Metropolitan Council, reprinted by the MN Governor's Planning Council on Developmental Disabilities. A booklet about personal futures planning for persons with developmental disabilities, their families and friends, case managers, service providers and advocates. Looks at planning a personal future, discovering capacities in people, building a network of support with person-centered teams, and "planning in concert." Excellent sensitivity to the worth and dignity and potential of each person.

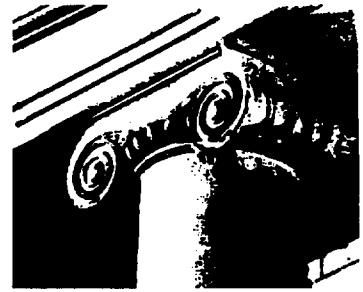
Perske, M., and Perske, R. (1988). *Circles of friends: People with disabilities and their friends enrich the lives of one another*. Nashville: Abingdon Press. 201 Eighth Avenue South, P.O. Box 801, Nashville, TN 37202, 800-251-3320. Among the most important things in life are friendship and caring and feelings. Anyone who cares about a person who happens to be somehow challenged in life should buy at least two copies of this book: one to keep and one to give away. Our purpose on this planet and the role of any good government at any level include learning how to care about one another and about how to translate that caring into something that makes life a bit better. The stories in this piece of artwork will help you to do so.

Strully, J., and Strully, C. (1985). Friendship and our children. *JASH*, 10 (4), The Association for Persons with Severe Handicaps. 11201 Greenwood Ave N, Seattle, WA 98133, 206-361-8870. Talks about the importance of shared relationships such as going to school together as a basis for developing relationships.

Read my lips: It's my choice... (1989). Originally developed by Wm. Allen for the Association of Regional Center Agencies' Integrated Services Systems Project; reprinted by the MN Governor's Planning Council on Developmental Disabilities. This is a tool for expanding freedom of choice for consumers. It provides consumer-oriented needs assessments, service plans, ideas for making the service system understandable and for promoting self-advocacy. The guide is written clearly so that people with developmental disabilities who can read, as well as advocates and others, can use it. A good source.

6. Service Coordination

and the services self-advocates can utilize



“... We need to find ways of honoring individual choice and offering people a sense of security. How much harder it may be to establish your own life when there has been little in its patterns to encourage you to believe it is your own...”

Ann Shearer: *Building community: With people with mental handicaps/their families and friends.*
London: Campaign for People with Mental Handicaps & King Edward's Hospital Fund of London,
King's Fund Publishing Office, 2 St. Andrew's Place, London NW1 4LB, 1986.

The way we see each other and the way we treat each other is important.

When we are responsible to assure that another person is provided with supports or services which are necessary for life, or to improve the quality of a person's life, then the way we see and treat people is even more important.

The types of services that have been referred to as “case management,” vary from area to area. They vary in WHAT is provided and they vary in HOW WELL it is done. These services share a common purpose and advocacy role.

This section will review case management, now being referred to as service coordination, in terms of how we look at people and in terms of how we access services.

Each person needs to look at this section as it relates to local case management services. Think about what is being provided. Think about how well it's being done. Decide what to do to make it BETTER!

Case Management services are the hub of service provision.

It is essential that case managers/service coordinators be very knowledgeable about their role and about the needs of the people they are to serve.

It is essential that training for case managers be on-going.

It is essential that case managers have the authority to secure needed services.

It is essential that caseloads are small enough so that case managers can be personally involved with knowing each person for whom they coordinate services and so they can be a rock-solid advocate on behalf of each person.

WHAT IS CASE MANAGEMENT?

Case management refers to services which are provided to people with developmental disabilities that will help them gain access to social, medical, educational, and other needed services (from the *Developmental Disabilities Assistance and Bill of Rights Act of 1987: P.L. 100-146*).

This includes “follow-along” services between an agency or provider, a person with a disability and that person’s family. The “follow-along” services are to assure on-going service coordination.

COMPETENCY:

■ Participants will be able to demonstrate their knowledge of the case management system and what services may be available.

Concepts:*

Case management should: **

- Identify the full range of services needed.
- Identify the range of resources available, including each individual's natural support resources and the public resources available.
- Coordinate the activities of all services and resources.
- Refer individuals to all needed resources.
- Monitor and follow-up to see if services are received.
- Monitor and follow-along to prevent problems or to identify problems in service provision through on-going contacts with all services utilized, and with the natural support resources (i.e., family and friends).
- Assess and evaluate the effectiveness of all services or resources used.
- Continually advocate with or on behalf of each individual's Quality of Life.

CONCEPT HIGHLIGHTS:

Case managers coordinate services.

They help to gain access to social, medical, educational and other needed services.

People with disabilities and family members can be their own service coordinators with support.

It is important that case managers see people and recognize their potential.

Case managers must be knowledgeable.

They must be strong advocates.

They must have a small enough caseload to spend time with each person they serve.

The case manager should ask for consumer opinions and be available for family questions.

The case manager should assure the implementation of program plans and evaluate how well they do what they're supposed to do.

Together, the case management system, the consumer, and the family need to assure inclusion, choice, participation, community integration and quality of life.

*Sections adapted from: "Shaping Case management in Minnesota..." 1991)

**from Caragonne, 1984

Services should be based on these values:

- Every individual has worth.
- Long-term relationships enhance self-worth.
- This is an interdependent world where we all share the responsibility to assure the health, education, and welfare of all citizens.
- Learning is an essential and important part of human existence.

Support to people with developmental disabilities should:

- Be non- intrusive.
- Be easily accessible.
- Be efficient.
- Be growth-enhancing.
- Promote inclusion into the community.
- Involve the opinions, wants, and needs of the person(s) receiving supports.
- Be age-appropriate.
- Enhance dignity.
- Encourage connectedness...and friendships.
- Promote a positive social role.
- Protect the individual's rights.
- Be cost effective.



- Produce positive changes in people's lives.
- Foster full citizenship for each individual.

Life and learning experiences encouraged by case management should:

- Support and maximize growth.
- Emphasize the whole person.
- Maintain or increase the person's sense of community.
- Make personal decision-making fundamental.
- Enhance the relationship-building capacity of the individual and of those who are important to him or her.
- Occur in a variety of settings.
- Include the provision of supports and adaptations.
- Include real experiences and their consequences.

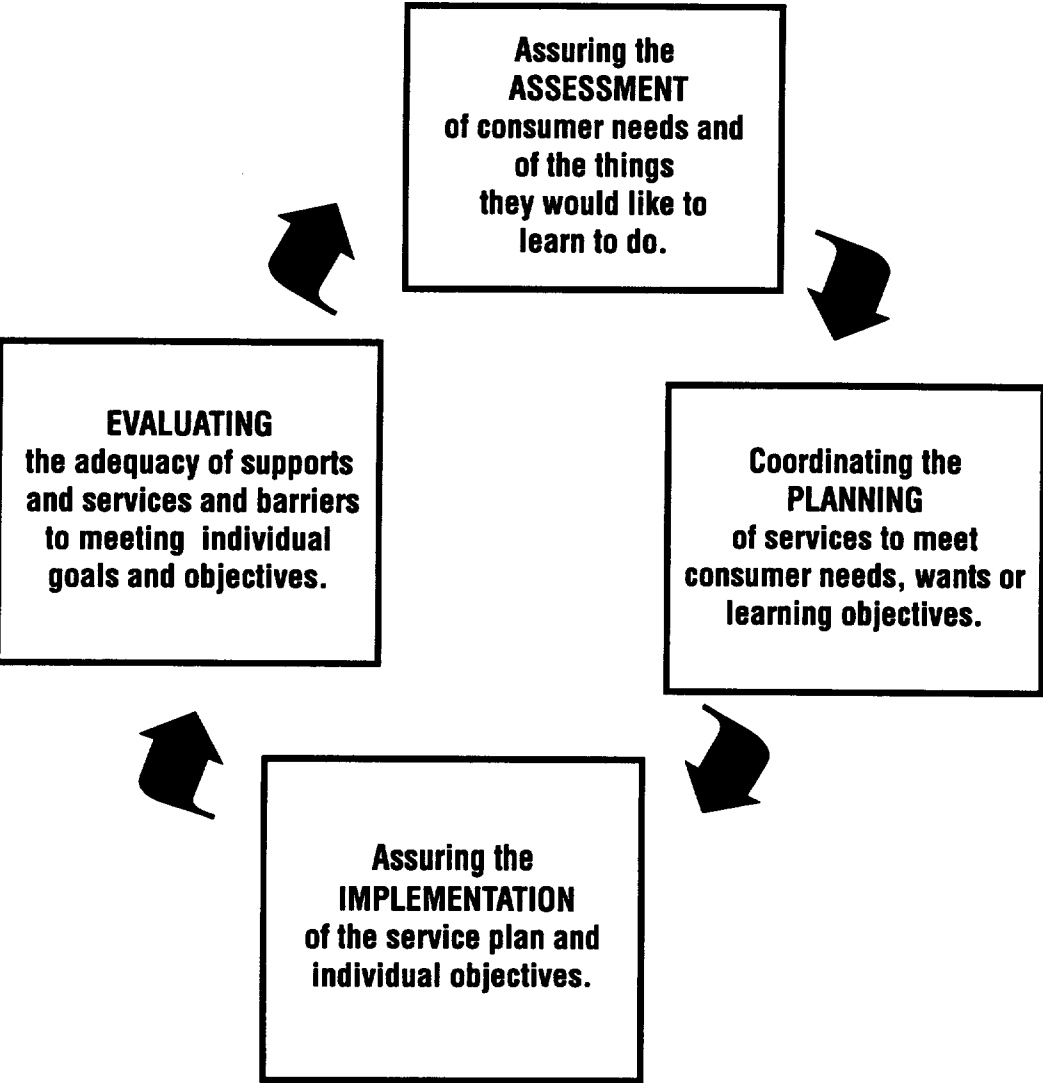
If you're a consumer, case managers should:

- Talk with you.
- Ask for your opinion.
- Help you with the things you need to learn.
- Do what he or she says he or she will do.
- Treat you with respect.
- Listen to you.
- Talk with you about your concerns or problems.

-
- Ask you about your likes and dislikes.
 - Ask you about what you would like to do or learn.
 - Be reasonably available when needed.
 - Help you to get the services you may need.
 - Talk with your family or friends when it's helpful unless you object.
 - Give you the opportunity to make or to be involved with making decisions about things that affect your life.
 - Encourage you to be involved with community activities, whether recreational or work or school - related, or religious or social.
 - Protect your rights.
 - Assure that you have opportunities to experience new things.
 - Coordinate the annual team meeting and arrange for support and services based on your needs and preferences.
 - Be concerned with your whole life.
 - Help you to enjoy living in the community and to become more independent.

CASE MANAGEMENT CYCLE OF ACTIVITIES

The goal is to improve the consumer's quality of life; to provide for his or her needs and to foster autonomy.



CASE MANAGERS:

Coordinate needs and services with and for the consumer.

Case Managers talk with consumers about their needs, wants, concerns, aspirations, feelings, likes and dislikes,

- regarding:
 - Dental
 - Housing
 - Medical
 - School
 - Work

- Family Involvement
- Friends
- Community Outings and Activities
- Transportation
- Religious Affiliation
- Future Plans
- Social Groups
- Protecting Rights
- Promoting Growth and Opportunities
- Supporting Friendships and Positive Relationships
- Promoting Positive Social Role and Image
- Supporting Consumer Choice

Key Readings:

Dunst, C.J., and Trivette, C.M. (1988). An enablement and empowerment perspective of case management. *Topics in Early Childhood Special Education*, 8, 87-102.

Hubbard-Ling, M., McAnally, P., and Wieck, C. (Eds.). (1989). *Case management: Historical, current and future perspectives*. Cambridge, MA: Brookline Books, Inc., P.O. Box 1046, Cambridge, MA 02238-1046. 617-868-1772. Twelve strong chapters that look at the history and effectiveness of case management, organizing the community, case management issues for the '90's, and other issues of importance to people concerned about service availability, coordination and quality.

Lippert, T. (1989). *The case management team: building community connections*. St. Paul: Metropolitan Council (reprinted by Minnesota Governor's Planning Council on Developmental Disabilities).

7. State-of-the-Art Technology



Ability without
opportunity is like a
seed never watered

“Technology is now a powerful force in the lives of most residents of the United States... The use of assistive technology devices and services by individuals with disabilities can reduce the costs... to society, individuals with disabilities and families of individuals with disabilities by reducing expenditures associated with early intervention, education, rehabilitation, health care, transportation, telecommunication services, and other services...”

Technology-Related Assistance for Individuals with Disabilities Act of 1988, P.L. 100-407

“Disability” has been described as “referring to any condition that challenges the development or functioning of an individual, such as sensory, physical, or mental impairments...” The term may be used interchangeably with “functional limitation.”

An “assistive technology device” is “any item, piece of equipment, or product system...that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.” An “assistive technology service” is “any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.” [P.L. 100-407].

The quality of life for many people depends on our creativity in developing and applying and funding adaptive devices which may increase their ability to communicate, to control their environment, to work, and to enjoy experiences in the world which many people take for granted.

COMPETENCIES:

- Participants will understand the reasons for and the importance of proper positioning techniques for people with disabilities.
- Participants will be able to describe examples of state-of-the-art technologies for people with severe disabilities.

Technology offers the opportunity to focus on the abilities, rather than on the disabilities, of people with functional limitations (disabilities). For many, assistive devices or technology-related services can make possible employment, more independent living, and inclusion and participation into the everyday affairs of the community.

According to one policy analysis report, modern technology has been a major force in improving the quality of life for people [with disabilities]. In programs throughout the United States, technological devices have been developed and adapted to assist people in many activities. However, the report also notes that “in spite of numerous innovative programs, resources, and expertise available in the area,” many people with disabilities still do not have access to the types of technology that could improve their quality of life.

CONCEPT HIGHLIGHTS:

Technology can assist a person who may have a functional limitation.

It can help people to see, to hear, to move around, to communicate, to work and to live more independently.

Technology is not always affordable or accessible for many people who could benefit from it.

Technology has helped us to learn how capable some people are.

More people need to understand what assistive technology can do.

More people need to hear the success stories.

Policymakers need to understand how assistive technology can save money by fostering independence and by helping people to have jobs.

Professionals and parents and consumers need to understand what is possible.

People need to be strong and clear in their advocacy for the increased availability of assistive technology.

Technology accommodates functional limitations.

With the support for fostering greater levels of independence and with the passage of key legislation,** positive opportunities for developing and applying technology have never been greater. Action must be taken to assure creative application and access efforts, to share information, to fund training, and to carry out the research and development that expands on the promise of technology for people with disabilities. The cost of doing so will be far outweighed by savings in productivity, economic growth, human dignity and well-being.

We cannot afford to lose this opportunity for developing and applying new technologies to enable people with disabilities: to pursue productive employment; to develop more autonomy and independence in determining how and where they live; to discover their talents and gifts; and to enjoy social and recreational opportunities in a way not possible without technology. Our focus must remain on the abilities of each person with a functional limitation and on how to use technology to the advantage of that individual (and, subsequently, to the advantage of each community).

SOME OF THE OBJECTIVES WHICH CAN BE PURSUED REGARDING ASSISTIVE TECHNOLOGIES COULD INCLUDE:

- Full implementation of the Americans with Disabilities Act.
- Securing technological devices for application and trial application for people whose needs are presently known.
- Increase the awareness of technological advancements among people with disabilities and their families and friends, professionals, policymakers and the general public.

*adapted from Abilities and Technology (1986). MN Governor's Planning Council on Developmental Disabilities.

** i.e., The Rehabilitation Act Amendments of 1986 and 1992, the Technology-Related Assistance for Individuals with Disabilities Act of 1988, and the Fair Housing Amendments Act of 1988.

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- Train professionals from a wide range of disciplines on the uses of technology for people with disabilities.
 - Provide access to adequate assessment, prescription and follow-up services for individuals with disabilities who need technological aids.
 - Establish funding mechanisms to allow for the purchase and maintenance of technological aids and related support services.
 - Establish advisory boards on the use of technology for people with disabilities to develop recommendations for public policy changes and applications and information dissemination. Membership should include consumers, and may include service agency reps, family or friends or advocates, third party payers, educational and government representatives.
 - Develop technical assistance and resource centers for promoting the understanding and application of technology for the further development of human potential and to further assist in the exercise of full citizenship by people with functional limitations.

EXAMPLES OF ASSISTIVE TECHNOLOGIES:

- A keyboard and a guiding hand for helping someone with autism to speak (facilitated communication).
- Manual and electronic communication aids to help a nonverbal individual to communicate and socialize with other people (augmentative communication).
- Making a switch larger or a device easier to access can increase the ability of people with physical disabilities to independently control their environment. This could range from turning the television, lights, and appliances on to answering the phone to opening doors and steering an electric wheelchair (environmental controls).

-
- Designing an insert for a wheelchair fitted to the shape of an individual (without compromising the ability to maximize trunk strength where applicable) can allow for maximum function and can prevent skin breakdown caused by pressure sores (custom seating systems).
 - Postural supports inserted into a power wheelchair help a student to maintain an optimal functional position that reduces abnormal muscle tone. They also improve a person's ability to perform desk and table activities along with friends and classmates and allows a person to participate in educational and recreational activities.
 - Independent mobility is a first step toward independent living. Many makes and models of power wheelchairs are available in which the placement of the control can be individualized to a person's particular abilities (mobility).
 - Modifications to a worksite may include raising the height of a desk, or fabricating work areas, or adapting machinery to make it accessible to employees with disabilities (vocational/employment adaptations).
 - A head mounted light beam for a ten year old with cerebral palsy allows her to operate a communication system that speaks for her and allows her access to a computer keyboard.
 - Ramps at state parks that allow people who can't use stairs to get around to key points of interest and to the waterfront to fish.
 - Lever door hardware and grab bars in the bathroom, lowered light switches and shelves, toe space at counters and the sink, and lowered counters and paddle faucet controls may allow someone in a wheelchair considerable independence at home (home modifications).

■ Ramps at state and local parks; restaurants, theaters, retail stores, businesses, and other places of public accomodation allow access to public recreational, commercial, and business opportunities (environmental modifications).

■ Lifts for public transportation and TTYs for phone systems and pointers and switches.

■ An environmental control system, including an amplifier on the phone to accommodate hearing limitations and a personal alarm system to notify health personnel if he has a medical emergency have improved one man's ability to manage his living quarters. This combination of high and low technology has given him the confidence and support to remain quite independent in his own home. "Equally important, this self-confidence has encouraged him to continue participating in activities out of his home." (*DD Network News*, 3 (3), March 1990).

Key Readings:

Facilitated communication. (1992). Syracuse University: Workshop, March 23-24, 1992. Includes various materials tied to the Facilitated Communication Project at the Division of Special Education and Rehabilitation at Syracuse University. Syracuse, NY 13210. Important information if you really want to understand facilitated communication.

The Americans with Disabilities Act of 1990. Public Law 101-336. Provides the legal basis for prohibiting discrimination based on disability and sets minimum legal standards for accommodating the needs of people with disabilities in employment; public services, including transportation; places of public accommodation; and telecommunications. Available by calling 1-800-949-4232.

The STAR Program: A system of technology to achieve results. This is one of a dozen useful reference brochures developed by the STAR Program, 300 Centennial Office Bldg, 658 Cedar Street, St. Paul, MN 55155, 612-296-2771. Other titles include: assistive technology and older Minnesotans, education and assistive technology, funding and assistive technology, consumer products and individuals with disabilities, transition and assistive technology, self-advocacy and assistive technology, barriers to the use of assistive technology, assistive technology and the Americans with Disabilities Act, Medicaid Waivers and assistive technologies, assistive technology and the workplace, assistive technology and home modifications for individuals with disabilities.

Biklen, D. and Schubert, A. (1991). New words: The communication of students with autism. *Harvard Educational Review*. Report on a study of 21 students with autism and the effects of using facilitated communication.

Haskew, P. and Donnellan, A. Emotional maturity and well-being: Psychological lessons of facilitated communications. *"Movin' on" beyond facilitated communication* (pp.3-21). Danbury, CT: DRI Press. An understanding of the process and implications of facilitated communication after two years of consulting with the pioneers of facilitation and observing facilitation in a variety of settings.

RESNA. An interdisciplinary association that is committed to designing, developing, and evaluating technology devices and delivering appropriate technology to persons with disabilities. Contact for a recent publication lists. RESNA, Suite 700, 1101 Connecticut Avenue Northwest, Washington, D.C. 20036.



8. *Supporting People in Their Homes*

*“Imagine...
It’s easy if you try.”*

John Lennon

What was unimaginable just a few years ago is happening. The battle to do away with the large, isolated, institution as a model of service for people with developmental disabilities is on the verge of being won. While there are some States that contend there will always be a need for relatively traditional institutions, the trend is clear. It seems apparent that sometime early in the next century the “institution,” the “asylum,” the “developmental center,” or the “state school” will become an historical artifact, a footnote in the social history of the United States and an icon for the ability of human services to be neither human nor of service.

So—the war is over; the Berlin Wall is down; people with developmental disabilities are in the community—now we can relax. Right?

Wrong! By clearing away the monolith of the institution, we can focus on the real challenges confronting people with developmental disabilities, their families, friends, and allies. Those challenges are about presence, participation, competence, choice, contribution—full inclusion as valued members of our communities. We now come face-to-face with the way service systems respond to families and their children with developmental disabilities, and to adults with developmental disabilities as they make decisions about where and how they wish to live. Ultimately, it hits us where we live; it all comes home.

The simple fact is that “home” is not the same thing as a “homelike environment,” an “alternate residential unit,” or an “SIP” (supported independence program). Support for families cannot be defined in terms of narrow, pre-determined service options like 14 days of respite a year, parent counseling, or “sibshops.” “Person-centered” and “family-centered” are not just new models for doing “I __ Ps” but are invitations to creatively design, *from the ground up*, what this family or this person needs. Can we finally bury the myth of “special places for special people” along with the monolith of the institution? Will we be able to make policymakers, administrators, university researchers and educators, direct service providers and our neighbors realize that community support of people with

developmental disabilities and families entails an essential change in thinking and acting?

There are plenty of ideas, policies, approaches, and resources we can call on to create a future for people with developmental disabilities that are not predefined by past models or even by the best examples we now have. Not long ago, home ownership by people with developmental disabilities, and giving families control over the resources they feel are necessary to support their family, were more unimaginable than the demise of the institution. Yet, these too are realities.

Together, we can create opportunities that are better than we can imagine. We can continue to make the unimaginable happen.

COMPETENCIES

- Participants will understand that a flexible, responsive system of supports for the families of children with disabilities is the corner stone for a true system of community supports for people with developmental disabilities.
- Participants will demonstrate an understanding of the need for all individuals to experience changes in life style across the life span.
- Participants will describe the importance of home ownership/control as one of the defining characteristics of adult life in our culture.
- Participants will outline the basic principles and strategies being used to support people with developmental disabilities in their own homes across the life span.

Creative Problem Solving

Imaging and creating futures for people with developmental disabilities are being discussed by supportive groups, or "learning organizations," and are marked by the following characteristics:

- Commitment to vision
- Acceptance of ambiguity
- Active raising of questions
- Try new ways to look at and do things
- Introspection on self and own life support
- Support for asking for help
- Personal involvement with the people they assist
- Acceptance of working outside usual program boundaries and routine
- Reach out to involve new people in their work
- Negotiate for what they believe people really want and need
- Take time to reflect and to invest in learning new things

John O'Brien

New ways of thinking and acting

In 1990 the Family Support and Empowerment Project at Cornell

University asked workers, involved with traditionally oppressed people as they struggled to gain control over their own destiny, to define what it meant to provide support.

They identified the following competencies for transforming traditional professional roles:

- Ability and commitment to identifying strengths in people and groups
- Genuine respect for diverse perspectives and lifestyles
- A capacity to listen and reflect
- An ability to subordinate one's own ego (to put one's self aside in the interest of the group)
- Skill and creativity in helping people become more aware and confident of their own abilities
- Knowing when to step back and the ability to help the individual or group assume decision-making and action
- Ability to analyze power relationships and help others to do so
- Knowledge about how to gain access to information
- Ability to reflect on and criticize ongoing processes, including one's own role in those processes

For all the progress we have made, most of our service models, funding structures, quality assurance mechanisms, and public policies related to people with developmental disabilities are derived from the institutional model. We have only begun to shake off these shackles and realize that community membership requires totally new ways of planning, funding, and supporting people.

Central to the transformation confronting us today is the issue of choice and control: Who is in charge? None of us denies the reality of people's disabilities—we are here because we are very aware of them. The need for assistance and support that is so much a part of the life of people with developmental disabilities should not overshadow their entire existence. We know that there is nothing inherent in raising a child with a disability that should require families to complete myriad forms and await endless approvals to confirm what families already know about the needs of their child. The need for support in certain aspects of life because of a developmental disability does not nullify the rights of adults to make decisions about how they wish to live. The challenge we confront is designing supports that respect and affirm the home, the family, and the choice of each individual.

***Adapt the idea.
Don't adopt the model.***

Josette Combes

Supporting Families. Many people with developmental disabilities have grown up at home with their families and lived as adults in our communities. Yet only in the last 20 years has there been a sustained movement to assist families in meeting some of the additional demands that come with raising a child with a developmental disability.

Until recently, public policy reflected a belief that raising a child was totally a private responsibility. We can begin to understand the origin of the advice to generations of parents to “put the child away and get on with your life” when we link this belief with pervasive negative societal attitudes toward people with disabilities. For families on the receiving end of this recommendation, the lack of assistance in the community and the attitudes of professionals and others meant that there was no “choice” involved in the placement of their child in an institution. Families simply did not have the resources to meet their child's needs and continue to function as a cohesive family. Parents who decided to ignore professional opinion and fight the battles of raising their child at home will tell you how they were continually called on to justify this most natural of parental decisions. Such was the profound dehumanization of people with disabilities in our culture. What was intolerable for a child without disabilities was not just OK for a child with disabilities, it was preferred. After all, “they” were not like other children. “They” did not need the nurture, warmth, care, concern, and commitment of their parents to develop into well-rounded people. The expectation was that “they” would not develop.

The combined efforts of advocacy organizations and court cases began to dismantle the institutional model. Policymakers found themselves being called on to provide some form of community services and supports to help “alleviate the stress of raising a child with a disability.” We began to see the growth of respite programs and parent counseling aimed at “assisting parents come to terms with their child's disability.” Calls were heard for public money to be invested in supporting the family rather than supplanting it. Advocates began to recognize that most states operated two distinct systems of child welfare. On one hand, the system for “normal” children emphasized the importance of strengthening and maintaining the family home and the right of children to grow, develop, and be nurtured in the natural family environment. On the other hand, the Mental Retardation/Developmental Disability system

CONCEPT HIGHLIGHTS:

The majority of people with developmental disabilities have always lived at home with their families or on their own.

Children with disabilities have the same rights as all children to grow up in the security of a nurturing family home.

Family support means a commitment to do whatever it takes to assist families of children with disabilities to live as a family.

People with disabilities need to be able to move out of the family home and establish their own identity as adults.

Control over your own life—particularly where and how you choose to live—is essential to the definition of adulthood in modern America.

Despite great progress, reform efforts of the last 30 years continue to place control in the hands of human service organizations.

Support of families and for adults requires a new role for human services built on a problem-solving partnership and recognition of the primacy of consumer control.

Providing an array of supports for daily living is far different from a continuum of residential options or developing individualized service plans.

“Supported living” provides a useful framework for exploring how housing can be separated from supports.

Individuals with the most severe disabilities can be supported in their own homes.

Housing must be separated from supports.

generally denied the importance of home life and failed to recognize any rights for the child.

With the hard won right to a free appropriate public education, supported by the documented effectiveness of early intervention, and galvanized by their own experience, grass roots parent organizations, since about 1980, have pressured policymakers to shift funds and priorities. They have insisted that all children have a right to grow up in a real home with a family. They have fought for family-focused services as the first priority in the state's developmental disabilities budget. As this family support movement has coalesced, a core of policies and practices has emerged that begins to sketch the outline of a true community system of services and supports.

The emerging family-centered approach is central to defining a new way of thinking and acting on the part of administrators and providers. The cornerstone of this approach is the understanding that families need to exercise choice and control over decisions which affect their daily lives. Parents need to be affirmed in the depth of knowledge they have about their children and family. Professionals are most effective when they abandon a judgmental diagnostic model of service and join in partnership with families to address the challenges faced by each family. When the community—including public, private, formal, and informal resources—joins with families of children with disabilities to mobilize resources and build connections, half the battle is won. Bonds among the person, the family, and community are preserved when these priorities are established. Inclusion and community membership are statements of a present daily reality rather than questions to be answered sometime in the future.

While great progress is being made in the area of family support, old attitudes still linger. Some states still admit children to institutions. There is no clear national consensus that group care settings, such as nursing homes and group homes, are totally inappropriate for children. Family supports still receive a small percentage of total state funds in developmental disabilities budgets. In many states, family support still leads a precarious existence because it is not firmly embedded either in the core of state legislation or state budgets. Like the movement away from institutions, the trends in family support are moving forward in a positive direction, but constant vigilance is needed to protect the progress made and push for increased responsiveness to families.

Tips for Working with Family Supports

1. Be informed about your rights.
2. Think through both what you need and what you want before meeting with potential service providers.
3. Be persistent and firm about what you need and want.
4. Bring along a friend when you meet with family support service providers. Another person can help provide the emotional support you may need. You can also enlist support from family members or your local advocacy group.
5. Advocate for family support providers. They may need consumers like you to push for funding, changes in regulations, etc.
6. Let providers know when they've been helpful to you.
7. Take notes during meetings to ensure there are no misunderstandings later.
8. Keep records, duplicate copies of forms, etc. from your family support services.

Housing Strategies

It is unfortunately true that many people with developmental disabilities have very limited financial resources. So as we increasingly de-link the provision of services and supports from the provision of housing we need to identify sources of funding to pay for housing.

A report to the President's Committee on Mental Retardation identified the following strategies:

Federal Programs:

- Section 8 housing certificate from HUD
- Public Housing programs funded by HUD
- HUD's Section 811 and FHA Section 515 program provides capital housing grants to non-profit organizations
- HUD's HOME program provides funding to increase affordable housing
- McKinney Act Permanent Housing Funds develop housing for people at risk of becoming homeless
- HUD's Community Development Block Grants help local communities develop urban areas, including housing
- Low Income Tax Credits provide benefits for owners or investors in low income housing

State/Local Efforts:

- Bridge subsidies for people on waiting lists
- Grants for closing costs, down payments, and setup costs
- Nonprofit housing corporations supported by state bond issues
- Programs of technical assistance and financial consultation
- Bank Community reinvestment obligations
- Cooperative housing arrangements

Supporting Adults. The ultimate family support is available when parents can begin to rest assured that their son or daughter has settled into a stable and secure adult life style. Unfortunately, most service systems provoke anxiety rather than offer security in this crucial area. When a person needs assistance in daily life, the best that most systems can offer is a place on a waiting list for a group home “slot.” This, in itself, is a cruel charade. Movement off a waiting list usually occurs not because the son or daughter has reached the top of the list but because of a family crisis. Families who hope for a smooth transition into adult life for their child and a change in their own lifestyle as their children leave home find instead that their adult child with a disability continues to live with them until they die or become incapacitated.

The constant fear that is fostered by this reality leaves many parents grasping at any hope for the future. The result is that decisions are made with little regard for the desires or preferences of the person with a disability. The priority for the parent is some security for their child’s future. Consequently, any placement now is better than the uncertainty of a future driven by crisis. It may not matter that both options have the same result for the adult with a disability: Placement in a facility where the rhythm of daily living is managed and controlled by others.

Adults with developmental disabilities—just like other adults—want a piece of the American dream. They want a **home** of their own. Home—your space, where you are in charge, where you can be yourself and not who someone else wants you to be. Home, the place that the United States Constitution protects from government intrusion. Setting up housekeeping—moving out—these are the transitions that mark the onset of adulthood. Unfortunately, the majority of the professional literature and the popular media continue to create the myth that people with developmental disabilities require “housing” in something called “home-like-environments.”

Thinking that continues to define the housing needs of people with developmental disabilities in terms of facilities betrays the depth of the institutional mind set in our culture. An industry has developed that supports the economic well-being of people without disabilities, sometimes at a substantial profit, while managing and controlling the lives of adults with developmental disabilities. This community system has great diversity.

We see small group homes managed by efficient responsive organizations that strive to assure that the people they serve have some degree of control over the places they call home. We also find the occasional large, corporate “adult foster care home” where people with developmental disabilities are commodities held hostage to assure a steady profit for the home owner. Every imaginable variation occurs between these two extremes. What remains constant is a firmly rooted characteristic of institutional care—paid staff managing the lives of people who have by their “placement” been designated as being dependent.

Several factors are creating a climate that is ripe for reform:

- An unresponsive system that places high stress on families and plays on their worst fears;
- An awareness of advocates and committed service providers that a “community system” designed and operated within an institutional framework doesn't fit;
- A persistent demand from adults with developmental disabilities that they want choices and control over their own lives.

Increasingly, “support” appears as the central concept in this new wave of reform.

A generation has struggled with the meaning of concepts like choice, control, quality of life, personal satisfaction, and community membership. This struggle has led the individuals who created “supported living” to recognize the power of the program/facility-centered model and how it reflects a way of thinking that is fundamentally alien to how human beings wish to live. As the segregation of the past is being rejected, several realizations begin to dawn:

- A continuum of services and the “least restrictive environment” create the illusion that people need a range of more or less tightly managed settings. The real need is not “restriction” or limited options but a unique group of individualized services geared to each person's needs and preferred living situation;
- The development of “homelike” environments for groups of people must be replaced with providing services and supports to individuals in “their own home.”

This insight involves breaking down the visible and invisible barriers of the institutional model. As a result, we must come to terms with a new relationship with people with disabilities. We need to really listen so we can hear: “I want an education, a home, a job, friends, a family.” Goals which were once written off as “unrealistic expectations” were only unrealistic within the sameness of an institutional environment. We need to quickly learn two very important lessons:

1. Our carefully managed, “normalized” environments are a major limitation on the people we said we were committed to helping;
and
2. Individuals with disabilities have a different view of what is truly support.

The change can be particularly striking for people who were trained to be professional helpers by assessing and teaching “them,” designing individualized plans and programs for “them,” and modifying “their” behavior. Professional roles can be redefined as assisting people to achieve a wide range of natural and diverse human goals and figuring out what it means to work with people with disabilities. The term “client” is no longer a meaningless euphemism which identifies individuals with disabilities as commodities traded on the human service market. Professionals are called upon to become responsive to their customers.

The profound nature of this change in consciousness leads to a redefinition of priorities. We concentrate on identifying individual and collective strengths rather than deficits. We explore personal hopes, dreams, and goals; and abandon “unrealistic expectations” based on diagnostic categories. Expectations related to the attainment of personal life goals supersede minimal expectations related to the achievement of programmatic goals. A crisis intervention mentality is replaced by a proactive crisis prevention perspective which identifies formal and informal resources, and develops multiple backup strategies. This approach is based on the premise that “support” is not a “program” that ends, but a long-term commitment.



Across the country there are a growing number of responsive organizations that provide truly individualized supports to adults with developmental disabilities, including individuals with very severe complex disabilities, in their own home. However, the vast majority of people who require some sort of assistance in daily life still find themselves in facilities that exercise pervasive control over their lives. Many parents continue to worry about the durability of their son's or daughter's system of supports—after all, they have been conditioned to put their faith in brick and mortar. Most service systems have not even begun to figure out how they can get out of the real estate business and convert resources to providing supports. The poverty which is so often associated with developmental disabilities raises new challenges as housing is separated from supports. If people are not living in “a program,” they need to go out into the market place and purchase housing. While these difficulties are not insurmountable, they underscore the many barriers that can still hamper adults with developmental disabilities from choosing where and with whom they live.

Key Readings:

Statement in support of families and their children. (1987). Center on Human Policy, Research and Training Center on Community Integration, 200 Huntington Hall, Syracuse University Syracuse, NY, 13244-2340, (315) 443-3851. This statement outlines the principles which should guide a public policy which recognizes the rights of children with developmental disabilities and truly supports families in raising children.


Family support, a check for quality. (1993). The Arc National Headquarters, PO Box 1047, Arlington, TX 76004, 1-800-433-5255. Identifies the goals of family support, tips for working with family supports, and a checklist for evaluating the quality of services and supports being received.

Housing policy and persons with mental retardation. (1994). Research and Training Center on Residential Services and Community Living, Institute on Community Integration, 212 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455-0223, (612) 624-6328. A report of the Working Group on Housing to President's Committee on Mental Retardation. Outlines issues, promising practices, resources, and barriers related to home ownership by people with mental retardation and other disabilities.

Klein, J. (1992). Get me the hell out of here: Supporting people with disabilities to live in their own homes. In J. Nisbet (Ed.), *Natural supports in school, at work, and in the community for people with severe disabilities* (pp. 277-339). Baltimore: Paul H. Brookes Publishing Co. In this chapter, the author, based on his experience in running a supported living organization, provides an overview of the new challenges that confront an organization that redefines its mission.

Agosta, J., Bradley, V. & Knoll, J. (1992). ***Toward positive family policy: Components of a comprehensive family support system.*** Human Services Research Institute, 525 Glen Creek Rd NW #230, Salem, OR 97304, (503) 362-5682. This analysis of the results of a national survey of family support practices highlights the issues that need to be addressed in designing a comprehensive responsive state level family support effort.

O'Brien, J. (1991). ***Down stairs that are never your own: Supporting people with developmental disabilities in their own homes.*** Syracuse University, Center on Human Policy, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340, (315)443-3851.



O'Brien, J. & Lyle O'Brien, C. (1992). *Remembering the soul of our work: Stories by staff of Options in Community Living Madison, Wisconsin*. Options in Community Living, 22 North Second St., Madison, WI, 54704, (608) 249-1585. This collection of stories written by Option's staff effectively communicates some of the qualities that make their work meaningful.

Taylor, S. J., Bogdan, R., & Racino, J. A. (Eds.) (1991). *Life in the community: Case studies of organizations supporting people with disabilities*. Baltimore: Paul H. Brookes Publishing Co. The sixteen case studies in this volume offer a thoughtful examination of some of the programs and agencies that have defined "the state of the art" in support for families and adults with disabilities in their own homes.



9. Strategies,

for advocates and self-advocates

You don't have
to be sick,
to get better.

Ian Pumpian

From irritants,
come pearls.

Lotte Moise

***“Knowledge will forever govern
ignorance and a people that mean
to be their own governors must arm
themselves with the power that
knowledge brings.”***

James Madison

***“Things don't just happen.
They are made to happen.”***

John F. Kennedy

How do you change the world? How do you change the behavior of a state or nation or an agency? “I’ve complained and complained and they still don’t change!” If we want to change the behavior of a state or nation or an agency...especially if they’re used to doing something the same way for years or if they think they’re right...

Then we have to be creative and we can’t be easily discouraged. There are very specific strategies that can be used to achieve change.

The best ones to use are ones that work.

You don’t know what “worked” until you’ve succeeded at your task so you have to be creative and tenacious and goal-directed and able to be persuasive that you’re right...until you find a strategy that does work.

Although no definitive listing of all effective strategies for all types of change can be created, the issues, concerns, and strategies noted here are some about which there may be a strong consensus by effective policymakers.

***“Let the course ahead be clear,
we shall not achieve great goals
with limited investments.***

***We shall not achieve mighty purposes
with petty actions. We will not find our way
guided by small dreams.”***

Hubert H. Humphrey 4-21-67

**Our world is
as limited as
we allow
the present to be
and as broad as
we can create
the future.**

COMPETENCIES:

- Participants will describe a vision for the year 2000 (and beyond) for people with disabilities.
- Participants will be able to describe how a bill becomes a law at both the state and federal levels.
- Participants will be able to identify critical federal issues and the process by which they can personally address their concerns.
- Participants will be able to demonstrate successful techniques for advocating for services to meet the needs of unserved and underserved individuals.
- Participants will be able to demonstrate proper procedures for running a meeting.
- Participants will be able to draft and deliver testimony for legislative hearings.
- Participants will be able to identify strategies for beginning and sustaining grass roots level organizing.
- Participants will be able to identify when and how to use the media to effectively promote their issues.
- Participants will learn how to meet a public official and express concerns.

Concepts:

CONCEPT HIGHLIGHTS:

We need to know what is possible.

We need to define the issues.

We need to develop a vision.

We need to work together.

We need to involve elected officials.

We need to clearly communicate with policymakers about what needs to be done, what's possible, what's right and what's wrong.

We need to involve the media.

We need to know what advocacy organizations exist (possibly to work with).

Consumers need to be a part of it.

We need to know how to run meetings.

We should learn how to organize.

We need to be creative.

We need to be persistent.

We need to win!

“Kindness” and “opportunity” aren’t always doled-out on an as-needed basis.

The fringe benefits of having a disability are not all benefits that most of us would stand in line to get.

Changing a system’s behavior is no easier than changing the behavior of a friend or relative. You should have an idea of what you don’t like... of what’s not good enough... You should also have an idea of what you think is right and of what services or opportunities or ways of doing things should be used. You should envision the type of world you would like to have. You should try to clarify for yourself “why is this right...” You should look around to see who else might agree with you (turning “you” into “we”).

You should look at the reasons why others might be reluctant to agree with you or to support your ideas. You need to look to see if your vision, or your shared vision, can be divided into smaller parts or steps which can be achieved more easily one part at a time. You need to explore with others, when possible, various ways to pursue your vision in part or in whole (Dream Big!)

You can change the world similarly to developing an individualized educational program plan or an individual plan of service. You want to have specific, behavioral, measurable goals and objectives. You want to decide which strategies to try first.

You want to decide who is going to be responsible for working on which objective and how they’ll proceed. You want to know when you’re going to monitor your progress toward each objective and how.

You need to understand when it’s time to regroup to re-examine your strategies, your successes, and the appeal of your current objectives.

MIDWEST ACADEMY STRATEGY CHART

AFTER CHOOSING YOUR ISSUES, FILL IN THIS CHART AS A GUIDE TO DEVELOPING STRATEGY. BE SPECIFIC. LIST ALL THE POSSIBILITIES



GOALS	ORGANIZATIONAL CONSIDERATIONS	CONSTITUENTS, ALLIES, AND OPPONENTS	TARGETS	TACTICS
<p>1. List the long-term objectives of your campaign.</p> <p>2. State the intermediate goals for this issue campaign. What constitutes victory?</p> <ul style="list-style-type: none"> ● How will the campaign win concrete improvements in people's lives? ● Give people a sense of their own power. ● Alter the relations of power. <p>3. What short-term or partial victories can you win as steps towards your long-term goal?</p>	<p>1. List the resources that your organization brings to the campaign. Include: money, number of staff, facilities, reputation, etc.</p> <ul style="list-style-type: none"> ● What is the budget, including in-kind contributions, for this campaign? <p>2. List the specific ways in which you want your organization to be strengthened by this campaign. Fill in numbers for each:</p> <ul style="list-style-type: none"> ● Expand leadership groups. ● Increase experience of existing leadership. ● Build membership base. ● Expand into new constituencies. ● Raise more money <p>3. List internal problems that have to be considered if the campaign is to succeed.</p>	<p>1. Who cares about the issues enough to join in or help the organization?</p> <ul style="list-style-type: none"> ● Whose problem is it? ● What do they gain if they win? ● What risks are they taking? ● What power do they have over the target? ● Into what group are they organized? <p>2. Who are your opponents?</p> <ul style="list-style-type: none"> ● What will your victory cost them? ● What will they do/spend to oppose you? ● How strong are they? 	<p>1. Primary targets</p> <p>A primary target is always a person. It is never an institution or elected body.</p> <ul style="list-style-type: none"> ● Who has the power to give you what you want? ● What power do you have over them? <p>2. Secondary targets</p> <ul style="list-style-type: none"> ● Who has power over the people with the power to give you what you want? ● What power do you have over them? 	<p>1. For each target, list the tactics that each constituent group can best use to make its power felt.</p> <p>Tactics must be:</p> <ul style="list-style-type: none"> ● In context ● Flexible and creative ● Directed at a specific target ● Make sense to the membership ● Be backed up by a specific form of power. <p>Tactics include:</p> <ul style="list-style-type: none"> ● Media events ● Actions for information and demands ● Public hearings ● Strikes ● Voter registration and voter education ● Law suits ● Accountability sessions ● Elections ● Negotiations

REVIEW OF ISSUES/ACTION PLANNING/ORGANIZING:

- Beyond caring and knowing what you like, or don't like, you need to select issues that you care about.
- The Partners training sessions have covered a number of issues which may make your blood boil.
- There are a large number of other issues desperately in need of advocates as well.
- For more energy, visit the best programs and the worst programs you can (so you have something to support, something to be outraged with, and a lot of 14th Amendment/Equal-Protection frustration that there could be such a difference).
- If you're part of an organized group, discuss the issues and select those that generate the most passion.
- If you're not part of an organized group (or if your group isn't willing to take action) look for other committed people to recruit to the cause.
- Hold public officials accountable.* Know your elected officials. Put their names, addresses and phone numbers next to your phone. Visit your elected officials as a constituent. Provide them with written information about your concerns. Write letters to them. Vote in every election. Support good candidates. Make sure they know about good programs and why they're good. Make sure they know about - and maybe visit - bad programs and know why they're bad. Let them see some of your vision of the way things should be. Otherwise, how can they make the right choices?
- Watch the media. React to stories misrepresented. Get to know local reporters and editors. Have a positive relationship and let them know when you're aware of some positive human interest success stories and programs that are models of the way things should be. They need to know when conditions are so bad that they need an exposé or a highly critical

review by the press. Reporters and editors need to know you well enough that, if they have questions or if a problem pops up somewhere, they want to call you first. That probably won't happen (as with elected officials) unless you nurture the relationship and develop mutual respect at times when the sky isn't falling.

■ If you're part of an organization, make sure you publicly give out awards for positive articles and positive behavior (in support of "the cause") by legislators, media representatives, employers, school personnel, or anyone else who deserves to be reinforced. We don't say "Thank You" often enough.

■ Be active in the electoral system, especially if there are positive candidates from any party who share your values and who need your support.

■ Join social justice organizations, parent organizations, advocacy and/or self-advocacy organizations.

■ Speak out against labels, abuse, neglect, suffering, segregated programs, the lack of consumer involvement, lack of needed programs or services or homes...

■ Actively support colleagues and friends. Show your support with calls, notes, thank you's. Stand up with and for people who are right.

■ Write letters. Letters to the editor. Letters of support. Letters to complain. Letters to suggest. Letters to officials. Remember that coalitions and letter-writing campaigns can also have a major impact. (Keep copies of letters for your files, for officials, for attorneys, and for follow-up).

■ Personal testimony...any citizen can give testimony. Learn about it. Ask about it. Just do it!

■ Education... Sponsor workshops, meetings, speakers bureaus, speeches, information brochures, posters, newspaper articles, conferences, consumer meetings...

■ **Communications...** In addition to newsletters, town meetings, letter writing, and awards, consider phone campaigns, advertisements, press releases, press conferences, booklets, pamphlets, seminars, slide shows, movies, resource guides, cable TV programs, radio or TV talk shows, exposés, public service announcements...

■ **Legal advocacy....** Law is a strategy. Review all it has done. Review what changes would not have come without litigation. Think about it.

■ **Fact finding forums...** These include citizen investigation panels, team meetings, community polls (of consumers, of parents, of neighbors, of the electorate at large), seminars by expert panels, radio and TV question and answer programs.

■ **Demonstrations...** These are an established part of the American landscape of social change. From women's suffrage to civil rights to the rights of people with disabilities, this is an acceptable and a powerful way of sending a message. "The powers-that-be do not expect traditionally powerless groups to make demands." Be creative! Be effective!

■ **To be effective, at some point we all need to know how to organize and how to run a meeting.**

■ **We need to be familiar with how to draft testimony.**

■ **We need to know what organizations exist and what missions they have and whether we need to work with them for change.**

Key Readings:

Bobo, K., Kendell, J., and Max, S. (1991). ***Organizing for social change: A manual for activists in the 1990s.*** Washington, D.C.: Seven Locks Press. Order by calling 310-549-9830 or writing to Seven Locks Press, P.O. Box 4466, Carson, CA 90749.

Eddy, B.A., Cohen, G.J., and Rinck, C. (1989). ***How to be an effective board member: Manual for self-advocates, manual for facilitation.*** Kansas City, MO: University of Missouri, Institute for Human Development, 2220 Holmes, Room 321, Kansas City, MO 64108. Materials can be used to train self-advocates, or can be used directly by self-advocates who can read. Examples are regional but would also be useful for people elsewhere.

Norley, D. (1972). "The care and feeding of legislators." ***The Exceptional Parent.*** P.O. Box 3000, Dept. EP, Denville, NJ 07834, Call 1-800-247-8080.

Summary of existing legislation affecting persons with disabilities. (June 1992). U.S. Dept. of Education, OSERS. 202-205-8241. Provides an overview of existing laws by categories such as education, employment, health, housing, income maintenance, nutrition, rights, social services, transportation, and vocational rehabilitation.

Making Your Case (1994). MN Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg, 658 Cedar Street, St. Paul, MN 55155. 612-296-4018.

Worrell, B. (1987). ***Leadership training manual: People First.*** Designed by People First, this manual shows how to start and operate a self-advocacy group. Includes guidelines for members, leaders, and advisors involved in self-advocacy. The Roeher Institute, Canadian Association for Community Living, c/o Fitzhenry and Whiteside, 91 Granton Dr., Richmond Hill, Ontario L4B 2N5.

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