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VALUES, POLICIES, AND PRACTICES:

CLOSING THE GAPS IN COMMUNITY INTEGRATION

BY

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Although this book deals with people with deaf-blindness, this particular chapter addresses the broader issues of the development of community integration over several decades in the US. The chapter asks several questions regarding the status of community integration:

Where have we been? (What is our history?)
Where are we now? (What is best practice?)
Where do we want to end up? (What are our goals?)
How do we get there from here?
How will we know it when we see it?

VALUES, POLICIES, AND PRACTICES: CLOSING THE GAPS IN COMMUNITY INTEGRATION[3]

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Abstract

Services for people with severe handicaps must begin with a clear value base. Service system policies and daily practices will then be derived from those values. Problems arise when the policies and practices of the service system do not reflect or promote the changing value base of consumers, advocates, and society. In order to create a truly integrated service system, values, policies and practices must fit together.

This paper presents the changes in values, policies, and practices over time, and discusses possible guidelines (in the form of report cards for services) for future service development.

Where Have We Been?

Many of us who are active in human services today as consumers, family members, staff members, or advocates for the past 25 years have witnessed broad ranging and dramatic changes in services to people with severe handicaps. Gunnar Dybwad, of Brandeis University, uses his 50 years of experience in human services to remind us of the very real changes that have occurred over time.

To better understand where we are now and where we want to go, we need to start with a look at where we have been. Many of the services, rights, and very concept that we take for granted today have emerged in the last quarter century. To an 18 year old college student or an administrator preoccupied with the budget for next year, 25 years many seem like an eternity. In another sense, it is a short period of time. Table 1 presents a partial listing of the changes in services to people with severe disabilities over the past 25 years.

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Table 1. National changes in values, policies, and practices.[4]

Year	Event
1963	President's Panel on Mental Retardation recommended a reduction in the number of people living in residential institutions.
1963	Passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act. This began the flow of federal money into institutional settings.
1965	Amendments to the Social Security Act created the Medicaid and Medicare programs that are today the major source of public funding for persons with developmental disabilities.
1967	Further amendments to the Social Security Act created Intermediate Care Facilities for the Mentally Retarded (ICF/MRs).
1971	The Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania. This court case established the right to education for children with disabilities, as well as the right to due process in educational decisions.
1972	The case of Wyatt v. Stickney in Alabama established the constitutional right to treatment and the right to the least restrictive environment.
1972	Amendments to the Social Security Act established the Supplemental Security Income program (SSI) to provide financial subsidy to persons in need including people with developmental disabilities.
1972	Wolfensberger published *Normalization.* This work articulated a new value base for services.
1975	By executive order, President Richard M. Nixon reaffirmed the national goal of returning 1/3 of the 200,000 people living in mental retardation institutions to the community.
1975	Public Law 94-142, the Education for all Handicapped Children Act mandated free, appropriate, public education in the least restrictive setting for all children with developmental disabilities.

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[4]. Information for this table is taken from Minnesota Governor's Planning Council on Developmental Disabilities (1987) and Bersani & Nerney (1988).

Table 1. National changes in values, policies, and practices, continued.

Year	Event
1975	The Developmental Disabilities Assistance and Bill of Rights Act established the Bill of Rights for people with developmental disabilities, and required every state to establish a protection and advocacy system to safeguard the rights of people with developmental disabilities.
1977	In the case of Pennsylvania Association for Retarded Children v. Pennhurst State School and Hospital, the court held that the fourteenth amendment guarantee of equal protection applied to people living in mental retardation institutions.
1981	As part of the Federal Omnibus Budget Reconciliation Act (OBRA),the so-called "Medicaid waiver" program was established to promote the diversion of Medicaid funds into smaller, community residential settings.
1981	Amendments to the Social Security Act created the so-called Katie Beckett waiver. Named for a young girl whose family wanted her to move home from a hospital setting, this program allows Medicaid payments for certain children living at home who might otherwise be institutionalized.
1988	Restoration of civil rights. By congressional override of a presidential veto restored civil rights to several groups including people with handicaps. These rights were curtailed earlier in the "Grove City" Supreme Court decision.

The institutional exposes of the 1960s made us painfully aware of the poor conditions in institutions. There were no standards of quality, no federal responsibility. There was no right to education at all, much less a right to education in the least restrictive setting. In fact, some figures indicated that as many as 1 million children with disabilities were excluded from schools altogether, and an additional 3 million did not receive appropriate education. There were no community residences, and all "good" professionals "knew" that people with severe disabilities could not live, learn, work, or play in the community.

Over the past 25 years we have seen the onset and dramatic increase in federal funding of institutional services, and the federal overseeing of minimal standards. We have seen the statement and implementation of a Presidential goal to reduce the numbers of people in mental retardation institutions. In fact as recently as 1977 approximately 85% of the expenditure in residential mental retardation services was for institutional services. By 1984, only approximately 60% of that expenditure was in institutional settings (Braddock, Hemp, & Howes, 1984). By the end of 1988 the balance will shift so that the majority of mental retardation dollars are being spent in the community.

Most of the words we use to communicate today and the concepts we use to think about services came into being in the past 25 years, including the term "developmental disabilities" itself. The list goes on to include "protection and advocacy," "ICF/MR," "Section 504." "SSI" "least restrictive environment," "integration," "normalization," and "mainstreaming."

Even our concept of civil rights has changed dramatically during this time period. Twenty-five years ago, there was no Civil Rights Act for anyone in the United States, and practices like poll taxes and literacy tests prevented large groups of people from functioning as full citizens. It is even more recently that we saw the development of the Civil Rights of Institutionalized Persons Act (CRIPA). Prior to that time, there was no clear mechanism to claim that a person's civil rights were being violated while in an institutional setting.

What has been the total impact of these individual events? There has been an increase in the availability of services, an increasing entitlement to services, and an increasing focus on physical and social integration (Bersani & Nerney, 1988). It is tempting to isolate these changes for each other and to view them as individual incidents: some changes in practice, some changes in policy, and a few as changes in the value base. To fully understand the evolution of the past 25 years, we need to see the interrelationships between changing values (toward greater openness, inclusion, and integration), changing practices (new techniques and technologies that make the value base practical), and changing policies (legislation, litigation, and regulations that promote or even require integration). These three spheres of social change (Bersani, 1987a) work together, lead by values, to then create a service and legal atmosphere to promote quality.

Where Are We Now?

Certainly the quality of services across the country is inconsistent. Many states or communities are doing better jobs than others. There are more exciting programs now than there were a decade ago when the President's Committee on Mental Retardation released its report on "Islands of Excellence"; however, there is still great diversity in levels of integration in service regions across the country. There is also great inconsistency by disability types. What is considered to be an innovative service in developmental disabilities may not be considered so in the area of mental health. Nonetheless, there are certain examples that clearly represent the "cutting edge" of service provision today, at least for those of us interested in promoting integration for persons with severe disabilities, including people with dual sensory impairments.

> In Denver, CO, Alex is a high school-age teenager with Down Syndrome and a bilateral hearing loss. He does not go to a segregated school. He is not in a self-contained class that mainstreamed for gym, art, and music. He does not go to the resource room for part of the day. He has a regular homeroom and goes to different classes each period with his age peers. Last year the students in biology class were dissecting frogs. Alex was one of those students. This was a meaningful activity for him, not because he will become a biologist, but because someday when a room full of the " guys" are reminiscing about high school days, and they brag about "the day in bio lab when we cut up the frogs," Alex will remember the experience, and, more importantly, the "guys" will remember that Alex was there with them. He is a

part of the school doing the things that students his age do.

In a small city in New York State, Jessie is a kindergarten-age boy with a significant hearing loss and a vision impairment, who uses a wheelchair. He does not go to a special school or to a special class. He is a part of a regular kindergarten class. Sometimes professionals come into the classroom to offer him special services; sometimes he leaves the classroom for a while to get other services. Much of the time, the "regular" teacher and aide provide Jessie with his education.

In Syracuse, NY, Tori is a 31-year-old man living in an apartment with two roommates. Considered mentally retarded as a result of PKU, Tori went to a segregated school all his life and as a young adult was rejected by the sheltered workshops in town. They said he was not "ready," so they placed him in "personal adjustment training." When a supported employment project was started in town, Tori was one of the first 18 workers selected. Today he works in a shopping mall department store, is on the payroll at above minimum wage, and is doing well. He did not learn the skills for his job in a "prevocational" program. He learned them on the job.

After several decades in mental retardation institutions in New York State, Mr. Jordan was exhibiting a variety of challenging behaviors: sticking sharp objects under his nails, picking at his face, pica and rumination and vomiting. His weight was only 95 pounds compared to an ideal of 135-165. Following a move to an apartment and a dramatic change to positive programming, several changes were noted. His self-injurious behaviors dropped to nearly zero, he has been out to a neighborhood bar, and on a vacation to Niagara Falls. He also is now placed in supported employment. His body weight is now 125 lbs. and the rumination/vomiting has stopped. A dramatic change in living conditions and programming made the difference.

Where Do We Want to End Up?

In 1986, the Canadian Association on Mental Retardation took a stand on the future. To begin with, they changed their name to Canadian Association for Community Living. This name change reflected a new emphasis on integration (community living) and a move away from a focus on the negative (mental retardation). As part of an agenda for change, CACL set the following position statement and seven goals (1987) as steps toward a goal of true community integration for all:

The Canadian Association for Community Living has identified seven objectives for 1992 as feasible though ambitious steps towards achieving the vision of Community Living 2000. Their attainment alone would not complete our vision for the year 2000, but they have been identified as *practical and realistic steps toward that vision* (italics added).

1. *Family Life*: By 1992, all children will have a meaningful family life.

2. *A Community Education*: By 1992, all children will go to school together with other children in the neighborhood [sic] and get an age-appropriate program to match their needs in regular school classes.

3. *Real Employment*: By 1992, everyone leaving high school will have the opportunity to get and keep meaningful work in integrated settings.

4. *Reduction of Sheltered Employment*: The number of people in sheltered workshops will decrease by 10% per year from the 1986 level as a result of people becoming employed.

5. *System Redesign*: The use of tax dollars to meet people's needs will be decided between the person who needs help and the provincial government.

6. *Political Commitment to Replacing Institutions*: By 1987, admissions to institutions will stop and evacuation will proceed at 10% per year based on 1986 populations.

7. *Quality of Life*: By 1992, a personal support network, securing the individual's place among family and friends, will be a commonplace approach to assuring one's future. (Canadian Association for Community Living, 1987, p. 14).

Perhaps the most remarkable aspect of these goals is not that they are far reaching and visionary, but rather that they are described by CACL as being "practical" and "realistic" (see italics added above). They are no longer saying that integration is an interesting theory. They now see integration as the most practical and realistic way of helping people with disabilities, including people with the most severe disabilities.

How Do We Get There from Here?...Closing the Gaps

As the field of developmental disabilities shifts toward a system that values community integration and full participation for all citizens, several "promising practices" have emerged that seem to promote and support the abilities of individuals to learn, live, work, and enjoy life in the community.

Family Supports: The goals of family supports are to prevent or reduce the need for out of home placements, and to increase the quality of life for a family while the member with a disability remains at home. Families may be supported by respite care, in-home supports and services, adaptive equipment and cash subsidies. Family supports are based on the assumptions that children belong with families, that services and resources can assist families to keep their sons and daughters at home, and that families should have a major role in determining the nature of supports that they receive.

Consumer Participation: Only a few years ago, "consumer participation" meant a greater involvement of parents in the services for their sons and daughters with mental, physical, and sensory impairments. Now, consumer participation has focused on inclusion of the direct consumer, the individual who actually receives disability services. New levels of consumer participation include consumers participating in meetings about their programs, participation in the hiring and firing of direct care staff, and participation on administering boards of directors. Integrated services on the future will have higher levels of consumer participation that ever before.

Self-Advocacy: Related to consumer participation, the self-advocacy movement is an attempt to empower consumer of disability services to assume more of an advocacy role in their own lives. Rather than rely totally on parents or others to advocate on their behalf, many direct consumers are learning to make their wants and needs known on their own. Self-advocacy can range from learning about one's rights as a consumer, to participating in governmental affairs as a full citizen. Integrated services in the future will use self-advocates effectively as a major part of efforts to plan, administer, and monitor services. Their participation will not be "token".

Community-Based Instruction: Perhaps one of the most significant shifts in teaching technology in the last decade is the movement toward more community-based instruction. Because the goal of public education for children as well as for adults is to increase interdependent functioning in the community, the community itself becomes the logical arena for the education and training. True community integration cannot be prepared for in simulated settings that provide artificial experiences: rather, community-based instruction will be needed to close the gap between instructional settings and daily functioning in an integrated community.

Heterogeneous Groupings in Natural Proportions: Traditional focus in special education and rehabilitation has been on homogeneous grouping, the clustering of individuals of similar levels of need into "ability groups" that can be taught together. This most often went hand-in-hand with creating environments (buildings, schools, or classes) that are excessively saturated with disproportionate levels of people with certain disabilities. Similarly, the new focus on natural proportions is an attempt to answer the question, "How big is too big?" If the number of people with disabilities is larger than what might be expected to occur naturally (5-15% depending on the disability) than the excessive saturation violated natural proportions. Innovative programs practicing heterogeneous groupings and natural proportions resist placing 6 people all of whom use wheelchairs in one setting, or grouping five children all of whom are labeled autistic all in one classroom. Such practices, while being more integrated than services of the past, still group people in excessive numbers, with an inappropriate focus on placing people "with their own kind." Innovative programs achieving new levels of personal integration will consciously work toward natural mixes of people with various types of disabilities and people without any disabilities.

Supported Employment: In most rehabilitation systems today, there exists a large gap between segregated employment in sheltered workshops and fully integrated, competitive employment. That gap is being closed by the development of supported work projects. In supported employment, the principles of community-based instruction and natural proportions are used in the development of job skills. Workers with disabilities learn job skills on the job site, in the natural environment. Only a few supported employees are present in any work setting so that the number of people with disabilities does not exceed the natural proportions. The individual on supported employment is trained and supervised by a job coach whose job is to support the worker, and then fade that support as the worker becomes a full employee of the business or industry that has served as the training site. Supported employment options are essential to close the gap between current practice and a future of integrated work for people with severe disabilities.

High Tech, Soft Touch: In the 1980s the technological boom that was experienced by the rest of America has finally reached people with disabilities. Enhanced communication systems and new adaptive devices are available to people with even the most severe mental, physical, and sensory impairments. There is no doubt that technology offers a great deal for the future. However, there is always a problem that technology will create distance between people with disabilities and people without disabilities. Integrated programs in the future will make maximum use of technology but will temper it with a soft touch to minimize the risk for dehumanization.

Public Consumer Monitoring: Nationally, new attention has been focused on quality assurance in disability services. Conferences today are filled with discussions of federal overseeing and "look behind" accreditation standards and licensure. However, most of the systems proposed for quality assurance rely on ever-increasing professional involvement with trained evaluators who are charged with investigating for compliance with minimal standards. While there is a role for this type of overseeing, parents, consumers, and advocates are pressing for an additional form of quality assurance as well: public/consumer monitoring. Monitoring projects such as the ARC-Ohio parent monitoring project are putting a new emphasis on the role of consumers, family members, and advocates as monitors of service quality. They point out that as nonprofessionals, they bring a different definition of quality, and a focus on homeness. While many surveyors will assess the quality of the "facility" and the "treatment," public/consumer monitors will monitor the extent to which people are being afforded a chance to live in a high-quality home. A fully integrated service system will need to use public/consumer monitors to close the gaps between adequate facilities and programs and high-quality homes for living.

People-First Language: One of the most compelling lessons learned from self-advocates is their insistence on what they call "people-first" language. They remind us of the fact that people with disabilities are in fact people first, and their disabilities are only secondary. In light of this fact, they recommend the elimination of terms such as "the mentally retarded," or referring to people by diagnostic terms such as "she is a rubella." Self-advocates also say that tagging "people" on the end ("mentally retarded people" or " a rubella person") are also insufficient. Preferable language includes, "a person with mental retardation," "a student who has dual sensory impairments," etc.

Focus on Relationships: The past 25 years have seen a focus in increasing community participation and personal integration for people with disabilities. At times however, the *process* of community integration is confused with the desired *outcome*, which is true personal interrelationships between people with and without disabilities. Professionals tend to focus on the clinical strides needed to "close the gap" for people with severe disabilities. In the long run, making friends with a few people without disabilities may help a person close the gap much more effectively than rehabilitative progress.

Federal Policy Change: As stated earlier, social change must take place in three arenas or spheres simultaneously: changing values, practice, and political conditions. One major section missing to promote the creating of integrated living and adult services for people with severe disabilities is the need for dramatic Medicaid reform. Currently the Medicaid system is the major funding source for disability services, and its continued bias is toward institutional, medical, and segregated services. In its place we need integrated, small residential options in regular community housing. The Medicaid program is in need of substantial redirection if it is to become a support for community services rather than a major impediment (Bersani, 1987b).

How Will We Know It When We See It?

There are many options for evaluating the level of community integration in a service program, or in the lives of individuals (Bersani, 1988). Some are quite simple, yet affective, and require no special training. Two such approaches have been published as pamphlets by the Minnesota Governor's Planning Council on Developmental Disabilities (1987a, 1987b). I sometimes find it helpful to use the analogy of a report card, only reversing the tables so that consumers, parents, and advocates get to grade the system rather then the system giving the individuals a grade. If one were to develop report cards for the residential, vocational, and educational systems, using the value base of total integration, they would look something like what is presented in the following three report cards.

An integration report card for school systems

Each school is to be graded in two major areas, current level of practice of integration, and current level of values that are supportive of integration.

Grade	Criterion	Evidence
A	*Practice*:	No segregated schools or classes. All students attend regular schools with their chronological-age peers in their own neighborhood.
	Values:	School system personnel affirm the value of integration for all students with special emphasis on the fact that so-called *nonhandicapped students benefit from integration as well.*

Grade	Criterion	Evidence
B	*Practice:*	There are no segregated schools or out of district placements. Plans are under way to phase out self-contained classes. More and more students with severe disabilities are being served in schools in their own neighborhoods.
	Values:	There is an acceptance of the value of total educational integration, but administrations admit that they need to learn more about inclusion of some of the children with the most severe disabilities.
C	*Practice:*	There are plans to close the remaining segregated schools. Few remaining children being served out of the district are returning to local schools.
	Values:	The system says that we can certainly do a better job of integration than we have in the past, but we may need to confront the fact that there are some people who can not be served in integrated settings.
D	*Practice:*	There is a moratorium on the development of segregated schooling options, and a task-force will explore alternatives.
	Values:	There is an openness to the possibility of integration, but there needs to be a better data base first. We can only proceed based on scientific proof of the benefits of integrated education.
F	*Practice:*	There are plans to expand the number of segregated educational facilities, especially purpose-built facilities designed for particular groups (such as a segregated school designed and built to serve only students with dual sensory impairments).
	Values:	There is a value statement reaffirming the value of all segregated services as not only the best we can do right now, but the best we can ever hope to do. Segregated schools are seen as a part of a total service network that includes long-term segregated employment and living.

An integration report card for vocational services

Each vocational service is to be graded in two major areas, current level of practice of integration, and current level of values that are supportive of integration.

Grade	Criterion	Evidence
A	*Practice*:	No segregated employment options (sheltered workshops enclaves or work crews). All people are employed in real jobs in integrated settings.
	Values:	Work is valued and available for all adults who desire it. All adults are seen as capable of benefiting from employment for both productivity and integration benefits.
B	*Practice*:	There are no sheltered workshops, and plans are under way to phase out enclaves and work gangs.
	Values:	Integrated work is held up as a value for all, but providers admit that they are not sure about how practical a goal it is for some consumers.
C	*Practice*:	There are plans to close remaining sheltered workshops. Only a few people interested in working do not have real jobs.
	Values:	Integrated work is held as more important than in the past, but there is pressure to determine that there are individuals for whom integrated work will never be a possibility.
D	*Practice*:	There is a moratorium on the development of new sheltered settings, and alternatives are being explored.
	Values:	There is an openness to the possibility of more integrated employment for some people who could benefit from integration.
F	*Practice*:	Plans are under way to develop additional segregated work and prework options.
	Values:	There is a value statement affirming the value of segregation. Segregated employment and various prework options are seen as desirable. Segregated work is seen as a continuation of a system of segregation that included segregated education and long-term segregated living.

An integration report card for residential services

Residential systems are to be graded in two major areas, current level of practice of integration, and current level of values that are supportive of integration.

Grade	Criterion	Evidence
A	*Practice:*	All children live with families. Adults live in groups that reflect the size of other homes in the community.
	Values:	Community living is seen as valuable for all people.
B	*Practice:*	There are no large, congregate, segregated settings. Plans exist to close or downsize the few remaining "large" community settings (six people and over).
	Values:	Small settings are valued, especially for children and people with the most severe handicaps.
C	*Practice:*	There are plans to close remaining group settings for children. Efforts are under way to "downsize" settings for 15 people or more.
	Values:	Small size is valued, but concerns persist about the economic and practicality of very small settings.
D	*Practice:*	A moratorium is in effect in the development of larger (more than "x" people) settings. Alternative are being explored.
	Values:	There is an openness to the possibility of some integrated living for some people. Care must be taken to not move people into community settings when it will be inappropriate.
F	*Practice:*	Plans exist to expand congregated, segregated living options. Plans include group homes for children and large specialized settings for adults.
	Values:	Segregated living is seen as a value for people with various disabilities, and it is seen as a part of a segregated system relying on education and work options.

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