

A New Way of Thinking: More Than Twenty Years Later



The Minnesota Governor's Council on Developmental Disabilities

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Since ancient times, people with developmental disabilities and their families have struggled to be accepted as equal members of their communities, people who are respected and valued for their abilities and contributions.

While the journey has been anything but smooth, people with developmental disabilities have made great strides in recent years towards attaining the basic human rights that people without disabilities often take for granted, such as:

- Access to appropriate, high quality, life-long education...*
- Opportunities for independence...*
- The right to choose where they live, who they live with and the type of support that they require to be productive...*
- Opportunities to engage in interesting community employment at competitive pay...*
- Opportunities to participate in appropriate, accessible community and recreational activities.*

Fortunately, people with developmental disabilities live, learn and work in a more inclusive society today. The dehumanizing conditions created by centuries of ignorance, discrimination, isolation and exploitation have given way to hope, dignity, respect and inclusion.

Looking Back on Twenty Five Years of Profound Change

The last 25 years, in particular, have been marked by significant progress, thanks to the dedication and creativity of self-advocates, family members, teachers, researchers, policymakers and professionals in the field of disability services. Several critical milestones achieved over the last quarter century have resulted in significant improvements that furthered the lives, livelihoods and inclusion of people with developmental disabilities. Important milestones include:

- A positive shift in public policy that goes beyond simply recognizing the rights of people with disabilities to instituting policies that actively protect these rights.
- A significant increase in financial and practical resources earmarked to create a richer quality of life for people with developmental disabilities.
- A movement within local communities and government entities to welcome and support people with developmental disabilities and their families.

Five key changes stand out:

- Continued wide-scale closures of institutions and development of community housing options.
- Investment of public funds in initiatives that create family supports controlled by individuals with disabilities and their families to allow them to live fuller, more independent lives.
- Recognition of the importance of natural supports and how they can be identified to help people with developmental disabilities achieve equal standing in the community.
- Critical changes in public policy that propelled the growth of family and community supports
- The shift to person centered planning and supports rather than provider driven services.

Closure of Institutions

For centuries, children and adults with disabilities were segregated in large state-run institutions where they received minimal care and little education at great government expense. Looking back just 50 years, you'll find life for people with developmental disabilities was dramatically different.

While a fortunate few were able to attend segregated schools or find “work” in protected employment workshops, the vast majority were isolated in massive state-run institutions. Sadly, for most people with developmental disabilities, these “warehouses” were the only homes they knew because the majority of parents at the time chose to relinquish their parental rights early in a child’s life in the face of overwhelming societal pressures and limited access to community supports.

By the early 1960s, more than 250,000 people with developmental disabilities lived in institutions across the United States. While a few institutions made weak attempts to help residents return to community life, the vast majority focused on attending to the physical needs of thousands of children and adults with developmental disabilities in their care. Even situations created with the best of intentions quickly degenerated into substandard, often abusive, care.

Fortunately, much has changed. Today, the vast majority of public funds designated to provide services to people with developmental disabilities are no longer earmarked to support vast institutions. The focus now is on supporting individuals and their families, but an institutional bias in funding remains.

Since 1968, the census of people with intellectual and/or physical disabilities residing in state operated institutions has declined every year. By the end of 2009, eleven states had closed all state-run institutions and another ten had dramatically reduced the size of their institutions. Slightly less than 40,000 people with developmental disabilities continued to live in institutions in the United States.

In an ironic twist, the cost of caring for one person at a public institution increased an average of 15% per year between 1970 and 1989, a time when acceptance of the possibilities offered by community integration was growing. States poured millions of dollars into institutions in a desperate attempt to bring the facilities up to stricter federal standards in the aftermath of high-profile scandals, exposés and lawsuits that marked the late 1960s and early 1970s.

Resources once devoted to supporting institutional care have now shifted to community supports and family services. In 1977, total spending on institutional care was three times the amount spent on community services. In 1989, funding levels for the two approaches was about equal. By 2004, the pendulum had shifted dramatically. Spending on community services and individual/family supports was four times that designated for institutional settings¹.

Individual Supports Take Center Stage

Four related support movements have come to the forefront during the past 25 years, each building on the legacies of its predecessors and focusing attention on the need to support individuals with developmental disabilities in their communities. Development of crucial community and family supports, increasing recognition that natural supports, with their limitless potential, are underutilized and readily available and the concept of self-determination all reinforce the belief that people with developmental disabilities can and should be welcomed into their communities.

Investment in Community Supports

The emergence of community supports paved the way for dramatic shifts in the way people with disabilities are perceived. Community supports refers to the range of medical, recreational, therapeutic and social services and programs administered and delivered in community settings to help individuals with developmental disabilities live the best, most independent lives possible and help families support a family member with disabilities in the family home or local community.

As the quality of community services increased and access expanded, policymakers began to

¹Braddock, Hemp, and Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005

recognize that a community support model was a more efficient and less expensive option than maintaining large public institutions. Fortunately, the popularity of the institutional model continues to wane.

As spending shifted from segregation to community integration in the 1980s, community services began to pop up around the country. Unfortunately, the dehumanizing practices ingrained in the institutions found their way into the first generation of community housing and supports. The struggle to move away from segregation, congregation and limited personal choice would continue for years. Some might argue that true community integration has yet to become widespread.

Despite growing recognition that helping individual's with disabilities achieve their full potential is more effective than shoring up expensive segregated programs, investments in family support options still ranks low on the priority list for most policymakers. In 2004, 61% of the 4.6 million people with developmental disabilities in the United States lived with or received care from family members. Another 28% lived in their own homes or with a spouse. Only 11% lived in supervised residential settings, such as public and private institutions, nursing facilities, group homes, supported living options, etc.

Family Supports Kept Families Together

As community support options matured and public support for institutions declined, the need to support the families of people with developmental disabilities took on greater urgency. Without this support, many families would be unable to care for a family member with disabilities and the need for institutions would continue. Today, the term “family supports” covers a wide range of formal and informal programs, physical support and financial subsidies coming from a variety of sources.

Common Examples of Family Supports

Family Support	Accessibility and Inclusion	Physical Support	Financial Health
Respite and day care services	Modifications to a home	Personal care assistant	Self-directed services
Family counseling	Adaptive equipment	Specialized medical services	Cash subsidy programs
In-home training and family education	Communications devices	In-home therapy	Voucher programs
Diagnosis, assessment and referral services	Modifications to a vehicle	Home health care	Medicaid waivers
Homemaker services	Transportation services	Adaptive clothing	Expense reimbursement
Sibling support programs	Recreation opportunities	Dental services	Adequate health insurance
Behavior management programs/support	Adaptive sports equipment	Nursing services	Futures planning
Service coordination	Technology	Medical devices	Financial planning

There is no doubt that publicly funded community and family services have made it possible for people with developmental disabilities to live, learn, work, play and contribute to the community. It is also true that publicly funded services rarely provide enough support for an individual to lead a full and meaningful life.

Sadly, allocations for critical family supports continue to lag behind spending in other areas. In 2006, family support allocations totalled \$2.31 billion, just 5% of total public spending on services to support people with developmental disabilities and their families. Although this represents a step in the right direction, this funding is not nearly enough to provide the crucial support needed by the more than 428,000 people with developmental disabilities who lived with a family member in 2006.

Natural Supports Open Community Doors

An unintended consequence of society's history of institutionalizing people with developmental disabilities is the assumption that they need "special" supports and services that are fundamentally different than those available to everyone else. Community members and organizations often forget that, as citizens, people with developmental disabilities have a right to the same services that everyone else enjoys. People with developmental disabilities are neighbors, classmates, friends, and family members. Thus, they have a right to the same supports offered to every other member of the community.

Natural supports are resources commonly available to everyone in the community, such as public transportation, activities sponsored by a local recreation center, grocery delivery services, etc.

From a service perspective, natural supports supplement community services. From a personal perspective, natural supports are the heart and soul of a meaningful life for people with developmental disabilities.

Self Determination Offers Financial Control

The fourth key movement that has shaped the lives of people with developmental disabilities over the last 25 years is the concept of self determination. A growing number of people with developmental disabilities are demanding self determination, self directed services and greater financial control. In other words, people with disabilities want to be able to set their own goals and describe their own dreams, decide what services support those dreams and how those services should be provided.

While self determination is a general term for choice, Self Determination also refers to a specific planning discipline developed by the *Center for Self Determination*, which includes a person centered plan that outlines an individual's hopes, dreams, strengths, capacities, preferences and support needs. Self determination is most effective when the individual has control of the public funds allocated to his or her support.

Forging New Realities: Disability Is Natural

Twenty years ago, Kathie Snow was a self-described “therapy mom” who dedicated herself and her home to doing what the service system told her was best for her young son. After attending Partners in Policymaking, an award-winning advocacy training program for self-advocates and parents of young children with development disabilities, Snow began to think differently about her son and her expectations for him. She met other families and learned her family was not alone. Her contacts with people with disabilities shook her worldview the most and she vividly recalls them describing how much they had missed in life because they were isolated by services.

“I realized that professionals can rob you of your hopes and dreams. They put you on a path of dependency. We needed to have the same dreams for Benjamin as we have for our daughter Emily,” she said. Kathie recognized that it was not the diagnosis of cerebral palsy that created the problem; it was what that diagnosis could lead to.

“Defining someone by their disability – the CP kid – is the greatest form of identity theft,” said Kathie.

The Snows decided Benjamin would not go to a special pre-school, continuing Benji’s therapies at home and as part of the normal school routine. But when Benji turned six, he said he did not want to go to therapy any more. Other kids in his carpool did other things with their time. So, the Snows quit doing therapy. “That was the day we got out of the disability world,” said Kathie.

When the family moved to Colorado, they located in a community with an inclusive school and enrolled Benjamin in T-ball and Scouts. Now 21 years old, Benjamin has never been segregated, is now attending college and working toward a degree. He was recently inducted into Phi Theta Kappa, the national honor society. He refused SSI after talking and thinking about the pros and cons – \$600 for doing nothing plus benefits but loss of privacy, disincentive to work, and being open to audit.

In the intervening years, Kathie has become an ardent promoter of disability as a natural part of life. She is a sought after speaker and animator and has developed all manner of materials, including books and a web site, that carry forward the message she heard Justin Dart deliver – disability is a natural part of the human experience.

“Advocates in the field have traditionally agitated for more services and more funding. **But we do not need more special programs that isolate and segregate people who have been labeled with disabilities.** We need, instead, inclusion in schools, communities, employment, and in other typical environments. To move toward that direction requires us to recognize that disability is a **“natural part of the human experience”**. People with disabilities are fine, just the way they are! Stop trying to fix them. Give them the tools, supports and accommodations they need so they can get on with their lives,” said Kathie.

“The service system ought to be the last resort, not the first choice. Services should be used only when natural supports fail. Choose a different path. If it is not enough or fails, the system will be there for you.”

Policy Propels Change

Much of the framework for today's community and family support system was built in the 1980s. Two key pieces of legislation pushed local communities to improve both the quality and quantity of support services, such as information and referral services, family training and counselling, access to short and long-term respite care, special assistance services, housing, transportation, recreation and crisis intervention.

The Home and Community-Based Waiver (HCBW) program was enacted in 1981 as an amendment to Medicaid. HCBW expanded the ways that Medicaid funds could be used to include in-home care, foster care, home modifications, etc., paving the way for more people with developmental disabilities to remain in their family homes or in homes of their own choosing. A year later, the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), often referred to as the "Katie Beckett Waiver," was enacted, authorizing individual states to use Medicaid funds to provide in-home care for children with disabilities who would have qualified for Supplemental Security Income (SSI) if they had lived in an institution.

On July 13, 1999, the U.S. Supreme Court announced its decision in the landmark Olmstead v. L.C. and E.W. reinforcing the right of people with developmental disabilities to live in the community. The decision required states to administer services, programs and activities "in the most integrated setting appropriate to the needs of the individual with disabilities." States were required to create critical support services and make federal funds available to expand community based services.

Building Full, Meaningful Lives

The closure of institutions and redirection of public funds to develop quality supports in local communities, along with recognition of self determination as an important aspect of a full life provides the foundation for an inclusive life for people with developmental disabilities.

A meaningful life is created when many pieces fit together – family and friends, social opportunities, a safe home, a broad range of employment opportunities and access to help when help is needed.

From “caring for” to “caring about”

In recent years, society’s focus has shifted from providing services designed to “care for” people with developmental disabilities to marshalling diverse resources to allow them to experience life on their own terms.

An essential component of a “good life” is inclusion in the community at real and meaningful levels. Examples of effective inclusion can be found in all corners of the world. The Local Service Coordination model in Western Australia, provides a clear blueprint for creating inclusive communities and providing highly personalized support. Aspects of this service model were adopted in the United Kingdom and led to major changes put in place by the government of British Columbia and other jurisdictions in Canada.

An important feature that sets Local Area Coordination apart from traditional approaches is its focus on developing personal relationships between local Coordinators and the individuals to whom they are connected. These connections and the resulting insights are often missing from more traditional service model where social workers act as the gatekeepers to needed services and financial resources.

Local Area Coordination of Western Australia: Small Scale Lever of Large Scale Change

Local Area Coordination is operated by the Disability Services Commission of the Government of Western Australia. Local Area Coordination (LAC) works with people with disabilities at the personal and community levels to make a practical difference in their lives and build more inclusive communities by focusing on natural, informal and community based supports. This is in stark contrast to the traditional U.S. approach, which focuses first on identifying formal, often more expensive and less efficient, programs and services. Because LAC focuses on supporting the goals, needs and potential of individuals with developmental disabilities and their families, the needs of the entire community also are addressed.

LAC has evolved over the last twenty years under the auspices of the Disability Services Commission responsible for advancing opportunities, community participation and quality of life for people with disabilities. The Commission provides a range of direct services and support, as well as funds non-government agencies that provide services to people with disabilities, their families and caregivers. One of the reasons LAC is so successful is the administration's personal understanding of the challenges faced by people with disabilities. At least five of the Commission's nine Governing Board members either has a disability, has a relative with a disability or has recent experience as a caregiver or advocate.

Local Area Coordination's framework is founded on the simple premise that the essence of a good life for a person with a disability is no different than that of a person who does not have a disability. Local Area Coordination consolidates many aspects of community and family support, including individual coordination, personal advocacy, family support, community development and direct funding and mixes activities and approaches from each human service discipline. Ongoing personal relationships between Local Area Coordinators and the children and adults with disabilities they have been connected with, as well as their families and caregivers, are crucial to gathering important input and feedback. Their initial focus is on identifying local, natural, low-level assistance options, considering more formal, structured services. Similarly, funding to purchase services is considered only if no-cost options are unavailable.

The aim of LAC is to make disability services and supports more personal, local and accountable, and to support people with disabilities and their families in their local communities. The LAC approach differs from more traditional support models in the following ways:

- Coordinators come from different backgrounds and professions.*
- Each LAC works within a defined geographical area and is based in local shop fronts.*
- Coordinators get to know and build relationships with 50 or 60 people with disabilities, as well as their families/caregivers, living within the LAC's boundaries.*
- LACs work with children and adults of all ages and stay with them across major life transitions.*
- LACs help direct funding, consistent with their view that direct funding is an adjunct to supports, rather than a primary solution.*

[Based on information contained in

Bartnik, E. and Chalmers, R. (2007). "It's about more than the money: Local Area Coordination as an innovative approach to supporting people with disabilities to get a good life and to creating more welcoming communities." In S. Hunter and P. Ritchie (editors) *Co-Production and Personalization in Social Care: Changing relationships in the provision of social care*. London, England: Jessica Kingsley Publishers.

and

Bartnik, Eddie (2008). "Active citizenship and community engagement – Getting serious about more positive pathways and relationships to contribution." In *Intellectual Disability Australasia*. June 2008.]

Learning and Working Together

Unfortunately, many people continue to think of special education as a “place” – a separate room where children with disabilities go to learn. The reality is quite different. The Individuals with Disabilities Education Act (IDEA) defines special education as instruction that is specially designed to meet a child’s unique needs to allow the child to learn the information and skills other children are learning. According to the National Center for Education Statistics, nearly 7 million children, aged three to 21, received special education services in the United States in 2006.

When properly and creatively implemented, special education is customized instruction that meets the unique needs of children with disabilities and allows them to maximize their abilities in an inclusive setting alongside children of all abilities. It also refers to services that support children with disabilities, such as physical supports and health care, one-on-one academic assistance, paraprofessionals, occupational, physical and speech therapies, etc. that enable them to learn. These services can be delivered virtually anywhere – in a regular classroom, at home, in a hospital or other setting. They don’t need to be isolated in a “special ed room” or “resource room.”

Jill England, Ph.D., an Inclusive Education Specialist, has researched the full inclusion of children with disabilities in a general education classroom and found dramatic proof that inclusion works. Her research found that:

- Following implementation of a full inclusion model at two Michigan high schools, graduation rates for children with disabilities soared from 50% to 95% in one school and from 70% to 97% in the other.
- 80% of students with disabilities who learned in inclusive classrooms had higher levels of achievement than their counterparts in “special class.”
- Creating inclusive school communities costs the same as a segregated system and usually less than student-by-student inclusion models.

Federal laws provide the cornerstones of the United States education system – IDEA 2004 (the Individuals with Disabilities Education Act of 2004) and No Child Left Behind Act of 2001 (NCLB). NCLB is the primary legislation affecting general education. IDEA 2004 is the primary legislation affecting special education. The primary goal of IDEA 2004 is to ensure that all eligible children with disabilities receive a quality education that meets their unique needs, incorporates necessary technology and support services, meets specific, pre-determined outcomes and is provided in the “least restrictive environment.”

In January 2008, the National Council on Disability released a report on the positive impacts of IDEA and No Child Left Behind. It concluded:

Students with disabilities appear to be doing better academically, and they also appear to be graduating with diplomas and certificates at higher rates than in prior years. Data suggests, however, that there is still cause for concern about the dropout levels of students with disabilities nationwide... we need a better understanding of the manifestations of new rules and regulations on these students. ...One of the most important results of NCLB and IDEA appears to be that students with disabilities are no longer ignored. To that end, NCLB and IDEA have had a significant, positive impact. Teachers, administrators, and the community are becoming aware of what students with disabilities are capable of achieving if they are held to the same high standards and expectations as their peers. (The No Child Left Behind Act and the Individuals with Disabilities Education Act: A Progress Report. January 2008)

A Home of One's Own

Until the end of the 20th century, “home” for people with developmental disabilities was synonymous with “residential services” – places in which people with developmental disabilities lived together. They lived in the community physically but were still essentially apart from it. In essence, people with developmental disabilities lived in “special homes” for “special people,” reinforcing the perception that people who needed support were unable to live in typical housing options.

Just a few decades ago, a major argument favoring institutions was that people with severe and multiple disabilities needed constant care. In the 1990s, the development of more and smaller community living facilities increased dramatically. By 2002, there were about 118,000 settings for one to six individuals with developmental disabilities, almost triple the number available in 1992. The number of residences for seven to fifteen people remained about the same, while the number of larger facilities (16 people or more) decreased. Although the availability of community alternatives has increased, waiting lists remain long.

A more dramatic shift has been the development of supports that allow people with developmental disabilities to have homes of their own, rather than live in houses owned and controlled by outside human service agencies.

A number of initiatives during the 1990s increased support to people with developmental disabilities owning homes of their own, including several federal programs developed to encourage adults with developmental disabilities to consider the full range of housing options. These initiatives included:

- Housing and Community Development Act of 1987 (P.L. 100-142)
- Stewart McKinney Homeless Assistance Act of 1987 (P.L. 100-77)
- National Affordable Housing Act of 1990 (P.L. 101-402)
- Farmers Home Administration's Guaranteed Loan Program
- Federal National Mortgage Association (Fannie Mae)

The 1990s also saw an increase in the type of supports available to people with disabilities that can be delivered in their own homes:

- The Community Supported Living Arrangement under the Medicaid Home and Community Services Waiver expanded availability of support services to people living in their own homes or in their family homes. The initiative increased consumer choice and control of their housing by separating needed supports from his/her housing arrangement.
- Reverse Equity Mortgages grew as an acceptable option for older families to access the equity they had built up over the years to finance housing and support services for a relative with a disability.

- Fannie Mae’s Community Living loan program was developed to assist families and community service agencies to finance small-scale community residences for people with disabilities. It has become a source of funding for consumer-controlled housing through the federal Home of Your Own initiative. By 1996, nearly half of the states offered a Home of Your Own program.

Key changes to Medicaid rules also made new housing options available to people with developmental disabilities by expanding Medicaid coverage to more low-income people with disabilities and families with children with disabilities living at home. This has helped to reduce the inequities that allowed people in institutions to qualify for Medicaid at higher income levels than their peers who lived in the community.

In 2001, the federal government embarked on the New Freedom Initiative, a multi-agency effort to “remove barriers to community living for people of all ages with disabilities and long-term illnesses. It represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life.”

The Olmstead Decision: Putting Community First

On July 13, 1999, the U.S. Supreme Court ruled that the Americans with Disabilities Act (ADA) requires states “to place people with mental disabilities in community settings rather than in institutions when the state’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individuals, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.”

The Olmstead decision left room for states to maintain “a range of facilities.” The court recognized that the ADA does not necessarily require a state to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community placement is appropriate for a particular individual. States also must consider whether or not such placement fundamentally alter the state’s programs and services.

In the wake of the Olmstead decision, the federal government issued a series of directives for states to comply with the ADA and federal grants have been made available to expand community based services. Dozens of states have organized task forces to develop implementation plans.

As early as 2003, however, all of these advances and plans were deemed at risk because state plans were systematically identifying long standing barriers to complying with the Olmstead decision, including:

- *Affordable and accessible housing.*
- *Transportation.*
- *Assessment tools to identify people’s needs.*
- *Information tools to link people with services.*
- *Data systems to monitor quality and track people at risk.*
- *Inadequate staffing, education and outreach.*
- *Limited availability of funded Medicaid waivers.*

Shortfalls in state budgets and the resulting fiscal crises led to a push to contain Medicaid costs, not expand them. A 2003 National Health Policy Forum paper concluded that “in light of such difficult barriers and a tight fiscal environment, implementation of Olmstead might be expected to grind to a halt in virtually all states.”

Fortunately, that has not happened. In 2005, the Center for Medicaid and Medicare Services had highlighted the following accomplishments:

- *From 2001-2003, \$158 million in Real Choice Systems Change grants was awarded to 49 states, Washington, D.C. and two territories to help states develop programs.*
- *These grants included “Money Follows the Person” demonstration projects in eight states to help states “rebalance their long-term support systems” (institutional and community-based options) and allow funding to follow the individual to the most appropriate, preferred setting.*
- *The Independence Plus Initiative makes it easier for states to request waivers or demonstration projects that offer families or individuals greater opportunities to take charge of their own health and direct their own services.*
- *The Transitions from Institutions Initiative allows the use of HCBS waivers to cover one-time expenses to transition from institutions to “their own homes in the community.”*
- *Creation of a Promising Practices repository of activities related to New Freedom Initiatives.*

Jobs and Careers

Twenty-five years ago, the idea that people with developmental disabilities could and should work in real jobs, for real wages in the community was just taking hold. That perception is slowly changing. In 2006, more than 115,919 people with developmental disabilities were employed full- or part-time at meaningful jobs and earning competitive pay. Unfortunately, there continues to be room for improvement.

In the 1990s, research and funding supported the involvement of people with severe disabilities in the community work force.

This research showed supported employment was an effective employment strategy for people with significant disabilities. Individuals who participated in supported employment generally had higher earnings and community interaction than their counterparts in sheltered workshops. Supported employment is paid employment in a community setting for persons with disabilities who need ongoing support to perform their work. This support can include on-the-job training, ongoing external job coaching, transportation or supervision.

Federal policy and funding continued to shift in favor of employment in competitive settings at or above minimum wage. By emphasizing competitive outcomes for individuals with disabilities, the 1992 Amendments to the Rehabilitation Act went beyond the anti-discrimination focus of the Americans with Disabilities Act issued in 1990.

By 2001, amendments to regulations governing the State Vocational Rehabilitation Program eliminated non-integrated and sheltered employment as an approved outcome for vocational rehabilitation services.

The Olmstead decision of 1999 together with the Rehabilitation Service Agency’s rule change combined to further transform the employment system. Elimination of extended (sheltered) employment as a successful rehabilitation outcome is in step with the rulings under the Olmstead decision.

In 2002, the U.S. Department of Health and Human Services reported actions proposed by federal agencies for key areas, including employment. The HHS report underscored the economic and personal benefits of employment.

If people with disabilities are to truly be a part of their communities, they must have the opportunity to work. Work is so essential that, without it, people with disabilities often face isolation and segregation from the very communities in which they wish to participate. The dignity, responsibility and economic independence resulting from gainful employment is the most effective way of reducing dependency on public benefits, enhancing self-reliance, changing attitudes and promoting community acceptance of people with disabilities.

Multiple barriers to employment of adults with disabilities include:

- Fragmentation of existing employment services.
- Isolation and segregation from mainstream programs and services.
- Lack of access to health insurance.
- Complex work incentives.
- Lack of control in the selection of providers.
- Attitudinal barriers based on historical stereotypes and misperceptions.

Many of the actions proposed by the Department of Health and Human Services are identical to strategies employed in the past – interagency collaboration, emphasis on transition services, assisting states to develop plans, etc.

While these actions create the context for change, their impact is yet to be determined. The number of participants involved in supported employment has changed little between 2001 and 2004 after being enthusiastically embraced in the mid-1990s. The number of people involved in supported employment climbed from 72,000 in 1994 to 112,000 in 2001 before leveling out. In 2004 there were still 112,000 people involved in supported employment. (Braddock, Hem and Rizzolo, 2005).

Assistive Technology Broadens Horizons

For a growing number of people with developmental disabilities, creative use of technology – whether a computer or a simple adjustment to a table – can mean the difference between being an active participant in life and watching from a window.

Assistive technology (AT) is any device, piece of equipment or service that assists a person with a disability to become more successful, independent, productive, in control and able to participate in community life. For people with disabilities, assistive technology is often the key to a whole new world – a world where they are included, have opportunities to live independently... work...go to school...meet new people...take part in activities that interest them.

Effective AT identifies a specific challenge, then identifies or creates a tool, device or piece of equipment that helps the user overcome a challenge or allows him or her to improve or maintain an ability. In many cases, a low-tech solution is the easiest to use, most reliable and most likely to promote inclusion, ensure safety, productivity and control.

Here are some ways that people with disabilities are using assistive technology to achieve their goals and be more independent:

Goal	Technology	End Result
Communicate	By: <ul style="list-style-type: none"> • Learning sign language. • Using a simple picture chart. • Using a computerized voice synthesizer. • Having an Ultra Voice Unit fit into a retainer. • Using a communication board. • Using a TTY phone system. 	You'd be able to: <ul style="list-style-type: none"> • Communicate your thoughts. • Tell others what you need want and prefer. • Share your stories and be part of new stories being created. • Tell others what you know. • Make new friends. • Participate in activities that interest you.
Learn	By: <ul style="list-style-type: none"> • Having your needs assessed by a professional so that a specific technology plan could be created. • Lowering your desk so your feet touch the floor. • Working with an Occupational Therapist to improve motor skills or working with a speech therapist to improve your ability to communicate. • Using adaptive scissors pens pencils and markers. • Using an electronic daily planner. 	You'd be able to: <ul style="list-style-type: none"> • Understand more. • Participate more. • Learn new skills and new ways of doing things. • Socialize more. • Make friends. • Be more successful.
Work	By: <ul style="list-style-type: none"> • Using a screen reader. • Installing larger switches that activate machinery. • Creating a joint work station with your job partner. • Using a job coach to help you learn a new job. • Using a split key board for your computer. • Using a pointer that allows you to use a computer. • Adding lower level storage to be more accessible by wheelchair users. 	You'd be able to: <ul style="list-style-type: none"> • Earn higher wages. • Be more successful at your job. • Accomplish the tasks assigned to you more efficiently. • Work independently. • Add new skills to build your career. • Earn promotions and new responsibilities. • Be part of a larger virtual community. • Make new friends

Live	By: <ul style="list-style-type: none"> • Changing door knobs to levers and keyed locks to touch pads. • Installing switches and controls that are activated by sound. • Using a service animal to help you with daily tasks. • Installing new larger controls on thermostats and laundry equipment and grab bars in the bath. • Purchasing a monitor that allows you to call a neighbor if you need help. • Using grabbing tools and other simple solutions to dress and care for yourself. 	You could: <ul style="list-style-type: none"> • Control who comes in and out of your home. • Take charge of your personal safety. • Decide what you want to watch on television and when to adjust the thermostat. • Accomplish more daily living tasks with little or no assistance. • Choose what to wear and put it on by you.
Play	By: <ul style="list-style-type: none"> • Using ramps, elevators and other accessibility options. • Using an all-terrain wheelchair. • Using an augmented communications device. • Using a service animal. • Using a computer to take part in a “virtual community.” • Using adaptive sports equipment. • Voting at an accessible polling place. 	You could: <ul style="list-style-type: none"> • Visit the beach, go for a “walk” in the snow, climb a hill, and play on a playground. • Help you. • Make your thoughts and preferences known. • Play a larger role on a team, in a theatre group, in a religious organization. • Be part of the political process.

A number of federal laws guarantee the right of people with disabilities to appropriate technology services and devices. These laws include: the Social Security Act - Title 19/Medicaid; The Rehabilitation Act; Americans with Disabilities Act of 1990 (ADA); Telecommunications Act of 1996; The Carl D. Perkins Vocational and Technical Education Act Amendments of 1998; and Individuals with Disabilities Education Act (IDEA).

From common sense solutions and simple tools to highly sophisticated “smart homes,” technology is allowing people with disabilities to live, learn, work and participate in life more fully.

Universal Design: AT to the Max

“Universal design” takes the concept of traditional assistive technology to a whole new level. Typical Assistive Technology solutions focus on solving a specific challenge by adapting or creating a device or piece of equipment.

Universal design, on the other hand, provides a framework for the design of places, things and information so that they are usable by the widest range of people operating in the widest range of situations.

Universal design is sometimes referred to as “design-for-all” or “lifespan design” because its goal is to create accessibility upfront, thereby eliminating the need to adapt a product, device or environment later, as a person’s need and abilities change over time.

The term “universal design” was coined by the late Ron Mace, founder of the Center for Universal Design, who said “the universal design concept increases the supply of usable housing by including universal features in as many houses as possible, and allows people to remain in their homes as long as they like.”

Acceptance of universal design has been furthered by legislation, such as the ADA and the Fair Housing Act, which mandate barrier-free environments for any facilities that receive public funds.

Creating a Shared Agenda

Despite the many advances in the way people with disabilities are welcomed and supported by society, many are simply add-ons to old systems and ways of thinking.

Public funds continue to rule the way support is provided. “Systems” and “programs” continue to dominate the way services are accessed. The disability services infrastructure is complex, difficult to navigate and, in many respects, out-of-touch with the real, practical challenges that individuals with disabilities and their families deal with every day when trying to achieve their goals for independence, inclusion and real, meaningful lives.

The challenge is to take the big leap and consolidate resources behind one agenda.

The last few decades of the twentieth century saw an unprecedented closing of institutions. More and more children experienced an inclusive education. Young people without disabilities no longer grew up, went to school and worked in a world without people with disabilities. More and more families had access to the supports they needed to stay together. People were supported to not only live in homes of their own, but to own homes of their own. More and more people with particularly challenging support needs have found meaningful work in the community and are making significant contributions to community life.

In light of these improvements, it might be hard to argue that positive change hasn't occurred. Yet, look below the surface and you'll find that, in most cases, there has *not* been a fundamental change in the way things get done on a day-to-day, community-by-community basis.

Despite decades of court cases and public exposés, institutions remain open and many children continue to be routinely institutionalized across America. In some states, service models haven't changed for decades and hard-won gains have been easily lost due to shifts in leadership or funding problems.

In the fall of 2005, eleven national organizations concerned with issues facing people with disabilities came together to develop and advance a common change agenda at the Alliance for Full Participation 2005 Summit. More than two thousand people with disabilities, along with their family members and the people who support, work, educate and live with them came together to create a unified vision.

Two key statements came out of that important gathering. The first was issued by SABE (Self Advocates Becoming Empowered). Conference participants were looking for a statement of priorities for the future. SABE offered clear direction – Just Do It!!

The “it” included the following:

- Get rid of the infamous and hurtful “r” word, do not label us. We will not put up with the “r” word continuing as part of an organization’s name even as initials. If you are working with me and for me then do not disrespect me.
- Close institutions.
- Get us real jobs. Close sheltered workshops.
- Give US the money to live OUR lives. Money follows the person means it is OURS not programs.
- We have the right to make our own decisions with or without the support from others. WE CAN RUN OUR LIVES. You receive millions of dollars in our name. We want to control this money as we are the EXPERTS.
- Support our movement. IT IS OURS.

In response, representatives from the numerous organization at the Summit concurred on what they believe must happen to make full participation a reality, not just words:

- Close all institutions and residential schools. Help people with lifelong disabilities to live in their home communities, in regular houses in regular neighborhoods.
- Help people with lifelong disabilities to find and succeed in real jobs with real pay, not in sheltered workshops and day programs. Recognize that everyone can contribute to their communities if given the opportunity and necessary support.
- Many families who have sons and daughters with lifelong disabilities need support to have equal access to full and rich family lives. Families with children or siblings with disabilities must not be forced into poverty or constant, lifelong worry. Everyone who needs support must receive it.
- People with disabilities must be part of all planning, governance, leadership and implementation of the programs that affect us. Remember, “Nothing about us without us.”
- The term “mental retardation” is hurtful. Stop using it!
- Public funds expended on behalf of people with developmental disabilities must be under their control and direction or, if more appropriate, under the control and direction of their families and trusted friends.
- People who work with people with disabilities deserve to earn a living wage with benefits.
- Medicaid is a vital lifeline for people with developmental disabilities. Any reform must protect access to Medicaid, promote inclusion for people in their communities and empower citizens to control the funds allocated for their support.
- Inclusive communities must be part of any solution.
- America is changing and becoming more diverse. This diversity must be honored and reflected in planning, governing and participating in communities.
- Poverty limits human potential. All Americans benefit when people with disabilities have access to real jobs with competitive pay, opportunities to start businesses and the chance to build assets for the future.
- American politics often pit people with intellectual and developmental disabilities and their families against those with other severe, chronic and lifelong disabilities. We must work together not against each other to create a common agenda for change.

While the organizations represented at the Summit brought their own agendas and perspectives, they were able to come together to agree on the core elements of an agenda all could share. This set of “demands” has helped disability organizations begin to move in tandem toward a single system focused on community and inclusion and move away from the conflicts inherent in today’s two-headed approach – one focused on segregation and exclusion, the other on inclusion and self determination.

For the first time, there is a united call to close institutions, once and for all. Self advocates also have called for the closure of segregated programs. The representatives support for options that further inclusion and community contributions. All agree that poverty presents a major barrier to full participation and ask that public funds be placed under the control of those receiving the support.

These joint efforts to forge a common vision based on a meaningful life in the community helps to underscore the power of working together toward common goals the disability community and farther afield. Competition for scarce resources within the disability community is a source of conflict and division between various organizations. When limited resources, particularly funding, is spread between multiple organizations with different ideas and agendas, even the most innovative thinking is difficult to implement on a small scale, even more so on a scale large enough to create true systemwide change. Not surprisingly, such conflicts and divisions are heightened when the disability community is forced to compete with other groups for limited resources.

Bringing People and Energy Together

There are many ways to build and harness the energy and resources required to allow people with developmental disabilities to have meaningful lives of their choosing.

At the individual level, circles of support have proven to be a powerful, effective way of bringing people together to support the dreams of people with disabilities.

Circles of support emphasize natural supports and identify opportunities for family members, friends, neighbors, professionals, community members and organizations to get involved in the lives of people with disabilities. This coordinated focus on a single individual requires community organizing that moves beyond the assumption that “services will take care of them” to “what can we do to help.”

This person by person approach builds information and experiences for system change.

Experiences around the world suggest that the struggles of the individuals connected to a person with developmental disabilities can help shape and advance more empowering approaches for all.

Circles of Support

A circle of support is a community of people who come together to support an individual’s personal goals in life. While the concept has many origins, the experiences of Judith Snow in Canada and the writings of Bob Perske were the original core sources that stimulated action around the world. For more than three decades, the ability of a personal circle to change an individual’s life has been borne out in the thousands of lives that have been touched around the globe.

The Circles Network in the United Kingdom is one of the most organized and persistent supporters of the Circles concept. The Circles Network describes circles of support as a group of people who meet together on a regular basis to help somebody accomplish their personal life goals. The circle acts as a community around a person who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. This person is in charge, both in deciding whom to invite to participate and in identifying the circle’s priorities.

A circle is not a service or tool. Circles are about seeing people as individuals who feel they need support in order to take control over their own lives. A properly facilitated circle empowers

all of the individuals involved and, unlike many service systems, does not reinforce dependence. Members of the circle, who may include family, friends and other community members, are not paid to be there. They are involved because they care enough about the focus person to give their time and energy to help that person to overcome obstacles and increase their options.

From the beginning, the Circles Network wanted to support circles all over the United Kingdom as a way of involving people who live on the margins and to push the envelope of inclusion to the greatest extent possible. According to Mandy Neville, Executive Director of Circles Network:

“We have grown largely organically. Our regional coordinators, and their networks, go with a single person, an idea, or a group of families around which they can generate interest and funding. We have moved area by area and developed an umbrella organization that can be a point of reference.”

The group’s nationwide umbrella organization sets The Circles Network apart from groups in North America where the idea of circles had its start. The Circles Network has a long history of working with individuals with disabilities and their families. It started with twelve years of core funding from a Trust, supplemented by project funding. Today, projects are accounted for on a full recovery basis. New projects usually start with a pilot or prototype where ideas are tested, modified, established, and eventually implemented in communities where there is interest.

A Closer Look: Circles Network Wales

Circles Network Wales assists people with developmental disabilities, their families, friends and organizations across Wales to develop Circles of Support.

The organization also works on projects related to building an inclusive society and empowering people with disabilities to achieve their ambitions.

A commitment to upholding the values of inclusion and a person-centered approach underpin all of the organization’s work.

The Academy for Inspiring Inclusion One is a unique way that Circles Network Wales supports individuals, families and communities as they develop circles and stand beside people who live on the margins. The virtual academy offers a range of learning opportunities for individuals and organizations across the United Kingdom and beyond. Through its affiliations with a number of universities, the Academy is able to offer accredited courses.



Bringing the Community Together

Far too often, people with developmental disabilities are invisible members of their communities, marginalized and living on the edges of society. If community members and organizations are aware of people with disabilities, that awareness is often a barrier to closeness and relationships – people with disabilities are seen as objects of pity or are assumed to be “taken care of” by human service agencies. Ordinary members of the community rarely wake up in the morning wondering how to get involved in the lives of people with disabilities.

One example of a modest effort to increase inclusion of people with developmental disabilities in their local community can be found at Sevenoaks, a community of about 110,000 people in the southeast of England. This modest effort had a large payoff and proved that increasing awareness and understanding of inclusion is crucial to success.

Building Community in Sevenoaks

Sevenoaks is a district just outside of London with three main towns and a population of about 110,000 people.

In 2005, Simon Goldsmith, Values Incorporated, received a small grant from the County Council to identify ways to work with the entire community to create the foundation for inclusion.

The project started at the local library. In the past, adults with developmental disabilities were sent to the children's part of the library. The group worked to set up an easy access area for people with low literacy skills, stocking books on tape, plain language materials, etc. The library started a group to help choose books and show adults with developmental disabilities how to use the library. Receptionists were given visual prompt cards, which have proven useful for all people, including older patrons with dementia.

The next step was to organize an event that called on community leaders to celebrate the lives of people with learning disabilities and ask for the community's help. A group of local secondary school students made a film for the event – "Getting a Good Life." The film did not focus solely on people with disabilities. It included the view of all sorts of people, including those with disabilities, who described their views of a "good life." The end result highlighted that people with disabilities wanted the same things everyone wants.

Of the 300 people who were invited, 120 people came and 36 organizations agreed to pledge their support. The outcomes had a very personal twist. As a result of this simple effort, people with disabilities began:

- Working as greeters with the National Trust at Knole House.*
- Participating in office experience days with British Telecom.*
- Working at a gardening service and in local shops.*
- A drama group was set up with local performers.*
- A book club meets Thursday mornings in the library and the easy access section in the local library is a destination spot for many.*
- A work program supports people to make plans for their futures in the towns and matches people with disabilities to new opportunities.*
- Being consulted about future developments proposed for the district.*
- Working with local police on a Police and Communities Together initiative contributing to diversity and quality training for police and community support officers.*
- Working as mystery shoppers to check the accessibility of local restaurants, access to sports and leisure activities, etc. and recommend changes.*

Bringing the System Together

The Alliance for Full Participation's 2005 Summit is one example of people coming together at a systems level to develop a common agenda that cuts across disability groups, and involved individuals, families, friends, professionals, and interest organizations.

The success of the Local Area Coordination process used in Western Australia offers another example of dramatic system change. The 20-year effort hinges on a commitment to a shared vision, reliance on pilot projects and ongoing evaluation of results, expanding to include more communities and disability groups, a commitment to quality, and the ability to back-up the approach's financial value.

In the United Kingdom, a series of consultations and vision statements also have realigned the system well beyond the issues facing people with disabilities. The white paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)*, is the first issued on developmental disabilities in the United Kingdom in thirty years. It sets out an ambitious program of action for improving services.

The proposals outlined in the paper are based on four key principles – civil rights, independence, choice and inclusion – and endorses a life-long approach that begins with integrated services for disabled children and their families through new opportunities for a full and purposeful adult life. It is backed across the government and its proposals are intended to improve education, social services, health, employment, housing and support for people with learning disabilities and their families and caregivers. The principles of *Valuing People* were re-stated in 2008 with the addition of personalization – a focus on employment, housing, self-directed support and individuals having greater say over their lives.

Valuing People outlined a clear vision to better the lives of people with disabilities. The vision was bolstered by the Disability Discrimination Act and Disability Equality Duties that require public services to treat all people fairly and equally.

In 2007, *Valuing People* was followed by a broad sweeping policy document with the goal of ensuring that older people, people with chronic conditions, people with disabilities and people with mental health problems have the best possible quality of life and access to independent living opportunities.

A cornerstone of this “Social Care” reform in the United Kingdom is “personalization” whereby every person who receives support, whether provided by statutory services or funded by themselves, is empowered to shape their own lives and the services they receive in all care settings. The approach includes direct payments and individual budgets.

In Australia and the United Kingdom, these improvements are rooted in the reform movement that advocated for people with developmental disabilities and later expanded to include all disability groups (Australia) and the bulk of the health and social services system (United Kingdom).

System Change in Western Australia²

Local Area Coordination has been a driving force behind the transformation of a traditional service delivery system in which people were required to “fit” into available services into a system of personalized supports and services built around one person at a time in their local communities.

For the first few years, Local Area Coordination operated in one community and was eventually expanded to other rural areas. The approach was piloted in one metropolitan area, followed by expansion to other metropolitan areas. After five years, the government expanded funding to include people with physical and/or sensory disabilities. By 2006, 135 Local Area Coordinators in Western Australia were providing support to approximately 7,500 people with disabilities.

This change in fundamental approach did not happen easily or overnight. There has been ongoing tension in shifting appropriate resources and power from the formal service system back to individuals, families and communities, requiring explicit recognition of natural authority and trust, as well as the changing role of professional and service staff. The core belief found at the foundation of LAC’s success is that an effective system incorporates an effective balance of formal and informal strategies where individuals and families can choose the level of self-direction and responsibility that best suits them.

The change process also has shown that fundamentally changing the system requires clear focus and a long-term strategy; it is not a quick fix. A focus on creating a good life and welcoming communities is at the forefront of this reform. What has mattered most, however, is the quality of support delivered. The strongest advocates are the individuals and families using it.

In public policy terms, there is growing recognition that over 70% of all care and support provided to people with disabilities in Australia comes from family and friends (Disability Services Commission 2005). It simply is not possible for the government and formal service delivery system to replace this support.

² [Based on information contained in Bartnik, E. and Chalmers, R. (2007). “It’s about more than the money: Local Area Coordination as an innovative approach to supporting people with disabilities to get a good life and to creating more welcoming communities.” In S. Hunter and P. Ritchie (editors) *Co-Production and Personalization in Social Care: Changing relationships in the provision of social care*. London, England: Jessica Kingsley Publishers.

And

Bartnik, Eddie (2008). “Active citizenship and community engagement – Getting serious about more positive pathways and relationships to contribution.” In *Intellectual Disability Australasia*. June 2008.]

Forging a New Reality

No one can predict the future.

We can, however, work together to shape the future into a time where all people are valued for what they bring to society, not for the support they require.

Great progress has been made in opening new horizons for people with developmental disabilities. Unfortunately, in recent years, the momentum that had been gathering steam through the latter part of the last century has leveled out. The spirit of innovation that lent energy to this effort has settled into complacency.

As a society, we need to come together to forge a new reality, one in which:

- Every person is seen as an individual, not as an ability or disability.
- All members of society are treated with respect and dignity.
- Every person has the opportunity to learn skills that allow them to participate as a valued member of the community.
- Everyone has the right to make choices, for better or worse.
- Meaningful employment is available to people of all abilities and which values the contributions made by all members of society.
- Every person has the supports needed to live in a safe environment that reflects their personal preferences, whether that means in a family home, an apartment or pursuing the dream of home ownership.
- Every person has opportunities for lifelong learning.

An effective shared vision must address these hopes and needs, plus a host of others. Our new vision must be forward-thinking and innovative. It must be open to new ideas. It must be willing to throw out old ways of supporting people with disabilities if those ways are no longer effective. It must keep its focus on individual rights while pursuing the policy changes needed to enforce lack of compliance.

Above all, our new, shared vision cannot be static. It must be open integrating all or part of the best practices that have been successful in other countries and other disciplines. It must adapt to reflect new ways of thinking about the challenges and opportunities that face people with developmental disabilities who are easily forgotten and whose voices are sometimes difficult to hear.

Time is short.

We must recommit ourselves now to creating a new, shared vision and join together to forge a new reality.



