The Community Living Paper

Promoting Life In Community
For Ohio's Citizens

Prepared For The Ohio Developmental Disabilities Planning Council
By Ohio Safeguards

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Promoting Life In Community
For Ohio's Citizens
With Developmental Disabilities

Prepared for the Ohio Developmental Disabilities Planning Council
by OHIO SAFEGUARDS

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Contents

Introduction

In 1983 the Ohio Developmental Disabilities Planning Council published a series of informational papers called the "Deinstitutionalization Papers". These Papers (the "DI Papers") presented and discussed ideas to guide decisions made by the variety of agencies in Ohio that developed and operated programs in response to the situations of people with developmental disabilities. The DI Papers were widely distributed, well read, and generally helpful to a continuing public deliberation about the quality of services to people with developmental disabilities in Ohio. Nearly ten years later, the Ohio Developmental Disabilities Planning Council has decided to publish another informational paper so that there can be another discussion of service quality and current service practice. This new paper, called the "Community Living Paper", is to be available for consideration both by those who are directly interested in people with developmental disabilities and by other individuals and groups that have a stake in improving the lives of all citizens of their communities.

Although there has been much change, since 1983, in the ideas that describe what good supports for people with developmental disabilities might be, Ohioans with such disabilities still find themselves caught up in patterns of response to their needs that are dominated by professionalized human services. Ohio's state institutions are smaller now, but they are still operating and, in the process, consuming a huge share of the state's investment for trying to help people with developmental disabilities. The county-based service system organized around Boards of MR/DD and the affiliates of those Boards has grown dramatically, both in the variety of services and supports offered to people and in the amount of public funds expended to pay for those efforts. Some of this growth has meant vastly enriched lives for some people with developmental disabilities; there have been enough examples of change for some children, adults, and families, to offer hope that larger-scale improvements for even more people could be on the way. Most people with developmental disabilities in Ohio, though, still do without much of the richness that could be available to them in community life. They are still poor, still undereducated, and still isolated from their neighbors and fellow citizens.

This pattern of experience of Ohio's citizens with developmental disabilities and their allies parallels, in important ways, the situation faced by many other citizens today. Increasingly, ordinary citizens feel that their incomes are threatened. Citizens are worried that the education their children receive will be insufficient preparation for the future. Many citizens sense that they are cut off from their fellow community members and that they and their neighbors may be powerless to affect the public and civic institutions that have such great impact on their daily lives. Over the last 40 years, the customary answer to the questions posed by such feelings has been "growth". Economic growth would promote income security. And, important for the discussion in the Community Living Paper, growth in the scope and array of professional services in arenas such as public education and public services for people with disabilities would alleviate all of the problems that people experience. Such problems were often attributed to the existence of "gaps" in the comprehensive scheme of services.

If human services and communities do listen to people with developmental disabilities and their allies and, then, act on what they hear, there will be great change in both the experience of service agencies and in the life of communities.

Now Ohio and the nation are poised at a time when the traditional answer of growth is at least temporarily unavailable. This "temporary" situation could, of course, last longer than experts expect. At the same time, the expectations of people with developmental disabilities and their families and other allies have not declined. Nor should they. Like other citizens with other concerns, people with developmental disabilities hope for lives filled with accomplishment. They both need and want high-quality personal assistance, much of which will have to be paid-for and some of which must come from well-trained professionals. They have, however, been promised and, therefore, reasonably expect a voice in designing and overseeing the help that they need.

Robert Bellah and his associates argue that the crisis of confidence in such public services as schools, courts, and services for people with disabilities must be regarded as a civic and moral issue—not a technical problem susceptible to professional problem-solving. Bellah suggests that there is a need for renewal of "a serious public conversation... to strengthen the institutions" that support democratic life in our communities.[1] The Community Living Paper proposes that a big part of a way out of the tension between rising expectations on the one hand and difficulties associated with reliance on "growth" on the other lies in increased listening to the voices of people with developmental disabilities and their allies. This listening must be followed by flexible rearrangements in the ways that both human service organizations and communities respond to people's voices, so that people with developmental disabilities have more control over what kinds of help they get, and when and how they get that assistance.

Listening to people who have for so long been voiceless and, therefore, powerless will be a new thing for both communities and human service organizations. If human services and communities do listen to people with developmental disabilities and their allies and, then, act on what they hear, there will be great change in both the experience of service agencies and in the life of communities. It is impossible to predict exactly what will happen. The Community Living Paper is, however, an attempt both to argue for a greater effort to hear what people with developmental disabilities have to say and to point in some of the directions in which a serious public conversation might lead.

Chapter One.
A Glimpse Back...

It is a cliché to say that "we are living in a time of transition." Nonetheless, the early 1990's are a time when the thinking of people with developmental disabilities and of their allies and, indeed, the thinking of those who organize and offer supports and services for people with developmental disabilities is changing. The change is centered on an increasingly clear understanding of the hopes and aspirations of Ohio 's citizens who have developmental disabilities by those people's allies and supporters. Within recent years the voices of people with developmental disabilities have been growing louder, partly because those people are fed up with some of the ways that communities and service systems have responded to their needs and partly because people's allies have begun to learn better ways to listen to and reflect their friends' voices.

There have, however, been other "times of transition". Within the living memory of people who are still interested and involved with supports for Ohio citizens with developmental disabilities are images of other times when big changes in ways of thinking occurred. The Community Living Paper begins with a set of remembrances of one of those times—the 1950's and early 1960's, during the flowering of what some historians have called the "parent movement" in the mental retardation field. There are two reasons why this glimpse backward is relevant to the Paper's task. First, looking back to another time of change will help people involved in 1990's decisions understand how current conditions developed for citizens with developmental disabilities. Second, a quick look at the past will offer encouragement to those interested in people who have developmental disabilities today, because the memories of 30-40 years ago contain reminders that communities across Ohio did respond in new ways to the needs of citizens with disabilities. It is at least reasonable to assume that, having responded in new ways once, communities have the capacity to do so again.

The process of tapping the memories of people who were active in the origination of community services for persons with developmental disabilities was limited in scope. The writers of the Paper visited and conducted interviews with people who are originators of local services in five different counties in Ohio—Butler, Cuyahoga, Delaware, Hamilton, and Ross Counties. The people who were interviewed are parents of sons or daughters who were characterized as having mental retardation. Some of the sons or daughters also had other conditions (e.g., cerebral palsy, epilepsy, autism, emotional/"mental" disorders, etc.) ascribed to them as well. It is not reasonable to argue that these parents' stories can represent in perfect detail the experiences, during the 1950's and early 1960's, of all families with members who have developmental disabilities. Remember that the term "developmental disabilities" was not in official usage until after 1970. It is reasonable, though, to say that the memories of the parents who were interviewed provide valuable glimpses into how communities in Ohio responded to the situations of people with seriously disabling conditions who did not leave those communities, who remained a part of community life, and for whom services or supports were demanded.

Within the living memory of people who are still interested and involved with supports for Ohio citizens with developmental disabilities are images of other times when big changes in ways of thinking occurred.

The late 1940's and early 1950's featured a noticeable rise in the United States' birth-rate—the "baby boom" about which almost every social commentator seems to feel obligated to speak or write. As always, a percentage of the babies born during those years had conditions, either noticeable at birth or evident within the first months or years of their lives, that would now be described as developmental disabilities. Again, as always (including the 1990's), parents of children with such conditions were often advised to avoid getting attached to the child at all or to "place" the child outside the family so that the quality of family life would not be threatened by the presence of differentness. There were, however, two things wrong with this advice during the "baby boom" era. First, too many children with potentially-disabling conditions were being born; there weren't enough of the "other places" to meet the demand. Second, and more important, families increasingly regarded the suggestions that they rid themselves of their own children as bad advice. Family-life was important, and parents—in ever larger numbers—began organizing so that it would no longer be considered crazy for them to believe that all of their children could stay at home and take an active part in family and community living.

These decisions that families made, in the face of almost overwhelming social and professional opinion to the contrary, took great courage.

> Fannie and Edward Baker of Cleveland recall being advised by medical personnel, when their daughter was born with Down's Syndrome in 1951, that there were "places" for children such as her. The Bakers considered this suggestion seriously. They got in their car and went to look at some of those recommended places. That was all it took. They knew that none was "OK", and they came to believe, during that round of visits, that home was the best place for their child. From that moment they began to try to organize things so that their daughter would have a good education and a meaningful place in her community.
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> Mrs. Helen Limoges, who lives in Hamilton, has two sons with developmental disabilities. When her older son was age 8, in 1952, she saw an article in a Sunday edition of the Cincinnati *Enquirer* about a new class that had started in Cincinnati for children with mental retardation. She remembers that she had "always had a dream" about such a class—about the right kind of schooling for her sons and for other children—in her own town. With the help of another mother whom she knew, Mrs. Limoges gathered names of families in Hamilton who were thought to have children with mental retardation. She and the other mother went to visit all of these families—16 of them in all—to try to spark interest in starting classes for children with mental retardation in Hamilton. Mrs. Limoges recalls how hard it was to find these families and how hard it was to talk with some of them.

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There Had To Something Better

When parents of sons or daughters with mental retardation decided, in the 1950's and early 1960's, that there had to be something better for their children, that decision included a determination that they would invent supports and services if those did not exist. In general, parents acted through two related channels. The first channel was the use of methods that are "associational"—methods characteristic of those customarily used by voluntary organizations that are trying to accomplish some sort of good purpose or to resolve a public problem. In many places in Ohio parents formed their own associations, and they turned to local organizations and clubs for help as well. For example, Mrs. Freda Arent of Hamilton recalls that families of children with mental retardation in Butler County were most grateful to the Hamilton Exchange Club because, on two different occasions, the club donated station-wagons so that children could get to school.

Secondly, parents turned for their models to the "community" and its traditional patterns for helping citizens. Seeking community models of how to get what they wanted for their children led parents to such agencies as their local public schools, their local industries, and their local public transit systems (among others). In four of the five communities where parents who originated local services were interviewed (Chillicothe, Delaware, Hamilton, and Cleveland), the first place where some of the parents went to get service for their children was to the public schools. In all four of these places, the schools responded, at first, in helpful ways.

Older patterns did not just disappear, however. The early efforts to get things organized for children and adults with severe disabilities were constantly threatened by the still-prevalent professional (and popular) idea that someone else "far away" would better be able to meet the needs of these people. Stuart Warshauer of Cincinnati recalls such threats when he was beginning to organize early "residential" services for people with mental retardation in the early 1960's. In a newsletter article, he warned:

> The old "let the state do it" philosophy is evidently being resurrected here by some persons who are active in community mental health programs. This is very dangerous. It is the same lazy logic that has kept Ohio in the Middle Ages in terms of care for the mentally retarded. Only individual and community effort makes government respond. (Emphasis added.)

In brief, many Ohio parents of sons and daughters with mental retardation, in the 1950's and early 1960's, responded to their children's situation by trying to organize three different kinds of assistance—schools, places to work, and places to live. This way of summarizing years of hard work in hundreds of locations around the state is simplistic, to be sure, but the sequence—schools for children, followed by work-places and residences for adults—does capture the essence both of what services developed and in what order they occurred.

Schools....

In Chillicothe, Cleveland, Delaware, Hamilton, and Middletown,

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classes for children of school age came first.[2] In all five places, the public school districts were helpful to parents as they made their initial efforts. It is useful to remember this because, until 1975, Ohio schools had very little responsibility for the education of children with "moderate" mental retardation. Officially, such children were adjudged to be "...unable to profit from further instruction", and were, therefore issued an "E-1 Card" (or "exclusion card") by the state Superintendent of Public Instruction. In the five places mentioned above, schools initially helped parents, even though they did not have to do so.

> When Mrs. Helen Limoges and her friend began scouting the city of Hamilton for other families with children who had mental retardation, they had the active assistance of Mr. Ray Taylor, who was an administrator for the Hamilton City Schools. When Mrs. Limoges and a few other families organized the "Council for Retarded Children" in March, 1952 and the Council made plans for the beginning of a class for a small group of children, Mr. Taylor helped by offering encouragement and advice and by directing the Council to more families to whom they could speak. The first class that got going was a summer class. It operated from June through August, 1952. The class was taught by a teacher from the Hamilton City Schools, and the class met in the Jefferson Elementary School. In September, 1952, the class was continued, in the same location, with a teacher hired (and paid) by the Council. Subsequent classes in Hamilton and Middletown met in public school buildings. Children who were educated in Butler County's "Council" classes went to school in public school buildings until the opening of the Fair Acres School by the County Board of Mental Retardation in February, 1973.

> The Delaware County Council for Retarded Children, Inc. organized its first classroom program in September, 1957. Richard Avey recalls that the Council arranged to use a basement classroom in the elementary school on West William Street in Delaware. The school's principal was Miss Boardman, and the building later became known as Boardman School. Miss Boardman told the Council that they could have the use of the room on a two-week trial. If anything went wrong, they would have to leave. After two weeks—a time when parents helped the teacher as much as they could—Miss Boardman not only asked that the class stay, but she also offered them furniture, supplies, some staff help when needed, and the use of the playground (although at times when the other children were not using it). Miss Boardman was as helpful as she thought she could be.

These early efforts to offer regular schooling near home for children with mental retardation were, however, not expected to be available to <u>all</u> such children. Both the parents themselves and state officials who inspected these early classes expected that there were some children who could not profit from this education either. Mrs. Genevieve Myers, of Hamilton, remembers that a state official tried to keep her daughter, Linda, from being enrolled in the local classes because Linda's IQ was allegedly too low. Helen Limoges recalls:

> "What was heart-breaking to me then was to meet the parents of a child with such a low level of functioning that he couldn't benefit even when a class was established.... Some of the hardest workers were those whose children wouldn't benefit." (Hamilton *Journal-News*, (9/24/79)

. . . schools initially helped parents, even though they did not have to do so.

Eventually, parents of some of these children followed the same path as other families earlier.

> Mrs. Jean Rominski of Cleveland was an organizer of classes for her son and the children of other parents whom she met. Their children were those who didn't qualify for the "County classes". They didn't qualify because they could not walk or because they could/did not use the toilet. Mrs. Rominski recalls that the program (the "School for Non-Ambulatory Retarded Children, Inc.") that she helped organize began, in 1963, in a church in Independence, Ohio. The class later moved to Hillside Elementary School in the Independence City school district. She remembers some of the interactions between the students in the program and other students from the neighborhood who attended that school. She recalls her disappointment when, some time after the County Board of Mental Retardation assumed control of the program, the classes were moved out of the school and into another building—a converted nursing home—where there were no other neighborhood children around.

Parents who organized all of these efforts to provide schooling for their children faced a problem common to most small voluntary efforts. They didn't have much money to pay for items like: teachers' salaries, classroom space, equipment, teaching supplies, and the transportation of their children to school. After 1951 the state of Ohio provided a small subsidy to "chartered" classes, but the rest of the money had to be raised by the parents themselves. Genevieve Myers remarks that, in the early days, "...we used more red ink than anything else." Some of the efforts to raise funds included: donations from service clubs (in Cleveland, a group known as the "Divot Diggers" purchased a van that was donated so that "non-ambulatory retarded children" could get to school), public dinners (spaghetti dinners, fish-frys), sales of a variety of items, and, in southwest Ohio, distribution of "special editions" of the Cincinnati *Post & Times-Star*. These special editions focused on the parents' programs for children with mental retardation, and the newspapers were sold by parent organizations to raise money. According to Genevieve Myers, these sales brought in several thousand dollars for the Council in Butler County.

The story about early schooling efforts for children with mental retardation in Ohio has always been that classes started in the face of the lack of interest on the part of public schools, that classes operated "on a shoestring", and that most of the classes operated in church basements. The "shoestring" part of the story seems to be right, but, based on the examples of Chillicothe, Cleveland, Delaware, Hamilton, and Middletown, the part about the opposition of schools and school officials is misleading. In fact, schools and school personnel often cooperated, sometimes with enthusiasm, to use the means they considered available to them to help children with severe disabilities receive an education.

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Places To Work

As children with mental retardation grew older, parents began to consider the establishment of places where their daughters and sons could go to work. They turned to a familiar community analogue—the factory—for their model. Organizers of early work-programs for adults with mental retardation also learned from observing examples of the now-familiar sheltered workshop, the roots of which go back well beyond the 1950's.

Jerome Metzel remembers the beginning of workshops in Cleveland. He recalls that an Episcopal minister at the Trinity Episcopal Church in downtown Cleveland was interested in arranging employment for adults with mental retardation and had started a small work program at the church. It happened that this minister was also a participant in an athletics group at Cleveland's Central YMCA, right across Prospect Avenue from the Church. Other members of the athletics group were businessmen (factory owners or managers, etc.) in Cleveland's industrial near east side. The minister convinced some of the businessmen to come across the street to see what adults with mental retardation could do, and some of these visits produced contract work for the fledgling work program.

Elaine Rieske of Ostrander was the first supervisor of the adult program in Delaware County. She recalls that, when what later became the "workshop" started in the autumn of 1967, the first work involved the workers in collecting, shelling, bagging, and selling walnuts from trees in the vicinity of the old Bellepoint School near Delaware.

When, in the late 1960's, Linda Myers of Hamilton was too old to go to school any longer, she began going to the Opportunity Workshop that was established in conjunction with Goodwill Industries in Hamilton. Early work included sorting donated clothing. Later, the work program moved to the nearby village of New Miami, and Linda worked on packaging jobs. Her mother, Genevieve Myers, recalls that Linda used a heat-sealer. Mrs. Myers also remembers that Linda learned how to use the Hamilton city bus to get to work in New Miami. She did this until the city bus company discontinued the service. After that, Linda rode a school bus to work.

Places To Live

Parents also began to recognize that their sons and daughters would live longer than professionals had thought. This meant that their adult children with developmental disabilities would need places to live. Many early efforts to develop what later became known as residential services incorporated the idea that the living places would be learning places as well. They would be residential schools, but they would be "home-like"—warm, accepting places that maintained the regard that the founding parents felt for their own children. Again, the organizational method was to gather a group of interested people (mostly parents) and form a voluntary association to work toward the goal of having these living/learning places available in their communities.

In Hamilton County, the Resident Home for the Mentally Retarded, Inc. was founded in the early 1960's. One of the first tasks for the new group was to raise funds. Over its first few years the group tried out many fund-raising ideas: applications for federal grants; sponsoring block parties, a Labor Day Festival, and a charity horse show; participating in a benefit softball game (against the "WKRC Bimbos"); saving enough Top Value stamps to purchase a school bus; sponsoring ferry-boat races on the Ohio River; and hosting benefit movie-premieres in the Cincinnati area for films like *My Fair Lady* and *The Sound of Music.*

What's worth noticing about these fund-raising schemes is that, in addition to raising money (that worked—the first "cottage" was opened by the Resident Home for the Mentally Retarded in Cincinnati in November, 1967) the activities were the kind that brought people together out of a common purpose.

Activities like this happened in a number of places in Ohio. What's worth noticing about these fund-raising schemes is that, in addition to raising money (that worked—the first "cottage" was opened by the Resident Home for the Mentally Retarded in Cincinnati in November, 1967) the activities were the kind that brought people together out of a common purpose.

A Shift In Control

Much has changed since the early 1960's. The personal opinion, or "voice" of children and adults with mental retardation was never sought as a help to deciding how supports and services that they would use would be organized. Early on, however, the voice of vitally-concerned family members was not just strong; it was in control of the development of new programs. A number of forces that have been at work in local programs for people with developmental disabilities have combined to gradually mute that family-voice over the past thirty years.

One such force has been the growing size and scale of the local programs themselves. Organizations that began, privately, by offering schooling to five or six children in classrooms rented (maybe for $1.00 a year) from public school districts have exploded into public sector enterprises that annually manage hundreds of staff in dozens of locations supported by multi-million dollar budgets. In some ways, this explosion, which is paralleled in states other than Ohio, might be regarded as one of the greatest examples of the success of voluntary, associational efforts at responding to a community social issue. Looked at another way, though, the explosion can be recognized as a sign of the failure of those efforts, in that the organizers themselves (or their successors—today's parents of people with developmental disabilities) have largely been silenced. Because the organizations have grown so large and complex, control over them and even effective voice about them disappeared from families' experience some time ago.

Another force that has helped to mute the voices of those who originated community services for people with developmental disabilities in Ohio (and the voices of their successors) has to do with the way that such services and supports are paid for. Ohio is unique among the United States in that a large proportion of the money for these community services is of local origin. There are certainly reasons why this is advantageous for people with developmental disabilities and their allies. The local origin of funding means a higher likelihood of identification with service-organizations by local citizens, and this identification may be translated into increased cooperation toward the goals the service-organizations have for the people they try to help. As well, local funds are not as tied down by excessive regulation, and, as a consequence, they offer the hope of flexibility in responding to the different situations of individuals.

There is another side to this issue, though. Local funds come from property-taxes, which must be approved by a majority of county voters in formal elections. This has meant that a regular feature of the life of local agencies that support people with developmental disabilities has been the

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"levy-campaign." There are two things to be noticed about these campaigns. First, they represent the majority of the "public education" activities about developmental disability that occurs in Ohio, and this means that, over and over again, the interest and well-being of people with developmental disabilities is portrayed as being identical to the interest of the agencies that are asking for funds. Second, the approval of levies for developmental disabilities service agencies—approval that in earlier times was nearly automatic—has been harder to obtain in recent years. Half of the levies proposed in Ohio's November, 1991 election were turned down by local voters. It is possible that ceilings are being reached.

In the early years, when the scale of efforts was more modest, organizers of programs asked their communities for all sorts of help—for money, for time, for contacts with other people, for material goods. More recently, the developmental disabilities field in Ohio has asked its communities only for money for programs. The connection between those requests and the lives of the people that lie behind them has been obscured. The voice of those with the most-vital interest in the lives of people with developmental disabilities has been muted, and, communities' sense of potential responsibility for the well-being of certain of their citizens has withered.

Stronger Voices Seeking Change

The lessons of this "glimpse back" for the future of Ohio's citizens with developmental disabilities are not, however, unrelievedly grim. The memories of those who originated many of the efforts to improve the lives of their (and others') children contain the good news that it was possible for communities to retain and actively support some of their members who have developmental disabilities. If that was possible in 1952, it is again possible today. If Ohio communities had the capacity to make new kinds of room for children and adults with developmental disabilities in the 1950's and 1960's, when a prevailing professional notion was that such people ought to be sent away, then those communities, presumably, possess the capacity to make other new kinds of room in the 1990's.

What is different now is twofold. Different things are being asked of communities. And, to an increasing extent, different people are doing the asking. A variety of events and efforts in the late 1980's and early 1990's have combined to add volume to the voices of people with developmental disabilities themselves. Now, because of dissatisfaction with earlier methods for making individual plans for people, there is a growing interest in personal planning methods that rely on the expressed wishes of the person being planned with. Now the influence of earlier civil rights movements has begun to be much more noticeable in the developmental disabilities field. Now the gathering strength of so-called "self-advocacy" efforts has made it more likely that others will listen to and learn from people with developmental disabilities. These voices are not loud enough yet, but they can be heard better now.

Now, because of dissatisfaction with earlier methods for making individual plans for people, there is a growing interest in personal planning methods that rely on the expressed wishes of the person being planned with.

And they're asking for different things. People with developmental disabilities, together with some of their families and their other allies, have been joined by many others from within the service systems themselves to request different kinds of responses from their communities.

Many of these people have learned that, for children with developmental disabilities to have the right kind of education, it is not necessary (it's not even advisable) to ask communities for donated, extra classrooms or expensive separate buildings. It is, instead, necessary to ask communities for places within regular school buildings and inside regular school classrooms, and for those buildings and classrooms to be of the highest possible quality for all students. It is noteworthy that:

- Butler County, which seems to have been one of the last counties to collect children with mental retardation into a separate and centralized school building, is the first county to systematically bring that separateness to an end.

- Delaware County built a separate school for children with mental retardation in 1975—the very year when such students "received" the right to a free education in Ohio. Today, just a handful of students of school-age go there. The rest of those children who were planned for in 1975 are in the local public schools.

- The Superintendent of the County Board of MR/DD in Chillicothe announced, early in 1992, a plan to phase down the separate school for children with developmental disabilities. The announcement drew an enthusiastic endorsement from the local newspaper.

People with developmental disabilities and their allies have learned to ask for schooling that takes place with all the other students in their communities.

People with developmental disabilities and their allies have also learned that it's not necessary to ask their communities to issue bonds, at expensive rates of interest for lengthy periods of time, to pay for separate places where people can go to work. It would no longer be required that Linda Myers ride the bus all the way from Hamilton to New Miami to find employment. It is clear by now that helping people with developmental disabilities find work that they enjoy, that pays better than anything they've ever done before, and that is meaningful to them is within the capacity of Ohio communities. There are now too many demonstrations of this capacity for it to be regarded as anything but fact.

People with developmental disabilities and their allies have learned that it is not necessary to sponsor movie-premieres (which hardly occur any more anyway) to raise funds to build and equip a "cottage" so that people can have a home. People now know that the housing-stock of many communities offers possibilities for many citizens with developmental disabilities, or, if the housing-stock is insufficient that there are others representing diverse groups in the community who can be joined to try to remedy the insufficiency. It is also clear that it is possible and even desirable to arrange supports around a person with developmental disabilities so that the person can live where she or he chooses and among people who are congenial to her or to him. It is no longer necessary to accept "package-deals" that resemble institutional life so that people with developmental disabilities can be at home.

It is also clear that it is possible and even desirable to arrange supports around a person with developmental disabilities so that the person can live where she or he chooses and among people who are congenial to her or to him.

When people with developmental disabilities and their allies use their stronger voices to ask for different things, the requests often cause discomfort in human service organizations, for reasons that will be described later in this Paper. John McKnight observes:

> It is important to recognize that the visions of human service systems for communities are often unacceptable precisely because they are not community visions. They are visions of systems creating little systems in local places. Neighbors who reject these micro-systems are not rejecting labelled people. They are rejecting a bad idea created by service professionals.[3]

This glimpse back has revealed that Ohio communities have not said "no" to the needs of their citizens with developmental disabilities—except sometimes to forms of help to which communities might have been expected to object. Jewell Long, a teacher/trainer who has helped adults with developmental disabilities in Chillicothe for many years, offers the reminder that Ohio communities' response to requests for help for people with developmental disabilities has been to do what is asked for. She says:

> Our community has always done what we wanted. We asked, first, for schools, and they gave us schools. Then, we asked for money; we got money. We wanted work for people to do in a workshop, and we got work. Then, we got more money. Lately, we've been asking for jobs that people can hold and that will pay more reasonable wages. Our town's businesses have supplied those jobs. The lesson is that we have to be very thoughtful about what we ask for, because the community is likely to give it to us.

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Chapter Two.
The Way Things Stand Now

The Continuum: A Still-Prevalent Way of Thinking About Service In Ohio

Ohio continues to invest large amounts of human and material resources in services to and for people with developmental disabilities. The majority of that investment supports service structures that are firmly rooted in state law and a forty year tradition of segregated services offered in facilities in virtually every county. The experience of many people with developmental disabilities who live in Ohio is that they become clients* of one or more of the programs operated or funded through County Boards of MR/DD. Other people's experience includes that of the state's system for special education in public schools—the unit-funding system that requires that people be categorized by disability-label. Upon graduation, many of these people come to the attention of vocational or adult service agencies—attention that often lands them in a community rehabilitation agency or in a program operated by a County Board of MR/DD. Recent changes in Ohio's definition of developmental disability may mean that all citizens with such conditions will come to the attention of the former mental retardation service system much earlier in their lives than they otherwise might have. The future of most citizens with developmental disabilities is constrained by the ideological and fiscal commitments required to sustain these existing structures.

Like most of the states, Ohio drifted into an approach to services for people with developmental disabilities (generally referred to as the "continuum") that continues to be prominent in the early 1990's. This approach has assumed that different programs, usually in different settings and planned for groups of people rather than for specific individuals, are necessary to meet the full range of service needs represented by people with developmental disabilities. The continuum approach has been based on the further assumption that persons with the most severe disabilities are appropriately served in separate spaces, while more socially and physically integrative settings have usually been seen as appropriate for only those individuals with the least severe disabilities. Others with disabilities have been served in other program options that fall between the least and most socially and physically integrative settings. The theory has been that if there were a sufficient number of places, one of them would fit any person regardless of that person's disability or need.

Unless something changes the likely future is that most people with disabilities will continue to grow up as strangers to their neighbors, peers, and fellow community members.

The continuum approach has further assumed that movement throughout the various service options from most socially and physically isolating to less so depends upon improvements in the person's behavior or acquisition of skill. A person is seen as "graduating" from one program to another. Although there may be positive aspects derived from involvement

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**The term, client, is derived from a Latin word that carries with it the meaning of "... to hear and obey." The Latin word was used to describe the status of serfs of medieval manors.*

in some programs and services, the continuum approach has resulted in major, life-defining problems for people with disabilities who are involved in these programs. Such problems include:

- People have been separated, routinely and early in their lives, from the common culture of their family, peers,* and neighbors. Most children have been grouped together with other children facing learning, behavior, and living challenges in places that hide them from their peers and community. Their designation as different has been promoted as the reason for their systematic absence from typical places, routines, and people without disabilities. Until the existing structures that were developed from Ohio's commitment to a continuum of facility-based, segregated services are no longer prominent, the likely future is that most people with disabilities will continue to grow up as strangers to their neighbors, peers, and fellow community members.

- People with developmental disabilities have been forced to earn their right to participate in more integrated settings. Many persons, especially those with severe disabilities, will never earn this right.

- The people with the most severe disabilities or with personal qualities that challenge helpers most have been the people least likely to have a chance to learn from adaptive models. That is, because people are grouped for service with others whose current performance is thought to approximate their own, their primary role models are people who may experience about as much difficulty performing as they do.

- The continuum idea has organized itself around <u>groups</u> of people whose primary connection with one another is that they are labeled. One result of this practice is that people's personal situations, preferences, family traditions, ethnic or social values, particular talents, or specific needs for useful supports and services cannot be regarded as the basis for program planning, design, or operation. This results in composite programs such as the "adult day care center for people with severe disabilities."

- Loss of personhood and its replacement with clienthood has separated people with developmental disabilities from the fundamental attributes of citizenship regarded as essential in our collective definition of liberty.

- This identity of clienthood that has become reality for people with developmental disabilities caught in the continuum is one of the primary rationales for the development of so-called case coordination or case management services. The continuum requires that a variety of settings be combined to "meet the needs" of a "severely disabled client." Case coordination becomes a management or organizing tool for the service structure, because success in the continuum means arranging the "right number" of service settings to fill the needs of each client. Case coordination, when it operates in the context of the continuum, becomes a way to perpetuate and often increase the clienthood status of people with disabilities. Precious monetary and human resources have been diverted from personal, specific, hands-on help or service for individual people to the essentially paperwork functions of assessment,

Money spent to support and sustain facility-based programs that gather people from significant distance and in large numbers is, therefore, unavailable to be spent on supports and services designed to meet the service needs deemed most relevant to particular individuals.

** We do not accept the commonly-heard usage that regards the "peers" of people with disabilities as only other people with disabilities. When we think of "peers" we mean others with whom one shares a similar chronological age and similar, although not identical, social-cultural background.*

eligibility determination, and placement.

- The entrance and exit criteria approach of the continuum strategy presumes that individuals can be type cast (e.g., as a "workshop candidate" and "activity center client" or " an adult daycare client"). The continuum approach has relied heavily on assessment procedures that are assumed to be predictors of a person's capacity over an extended period of time. These notions have reinforced the idea that certain people can be served only in certain types of settings and that certain programs and services can be developed only in a specific setting.

- The continuum strategy has fostered an emphasis on specialized facilities and congregate settings. A substantial amount of the resources allocated for program services and supports has been spent on operating buildings. Resources are also consumed on the administration required to support and maintain a large number of staff and service recipients housed in and transported to one or more large service facilities. Money spent to support and sustain facility-based programs that gather people from significant distances and in large numbers has, therefore, been unavailable to be spent on supports and services designed to meet the service needs most relevant to particular individuals.

- The continuum idea presumes the dependency status of the people it is designed to serve. Funds to support services and programs are given to organizations and not to individual people with disabilities (or to their families or trusted representatives). Resources represent power and presumed authority. In the current way of organizing things, both the resources and the authority for decisions about what a person "needs" are vested with a service agency. Without a legitimate entitlement for an equitable distribution of resources and authority, the person with developmental disabilities may become more a commodity in the eyes of service agencies than a colleague with whom agreements and contracts are negotiated.

These are real outcomes for people with disabilities who find themselves caught in the continuum idea about service design, practice, and structure. These outcomes identify issues that are critical to quality living. Dependency, segregation, labeling, and depersonalization are real results of both history and current practice for people with disabilities. Without change and a continual transition away from the continuum, the futures for people with disabilities will be much like the experiences that many people with disabilities have had and are having now: lives as "clients" first; lives where a label of difference begins, early in life, a process of separation that continues throughout life; lives without much of the power that comes from having a fair share of the resources and authority vested with them and those who stand with them as valued members of family and community.

The continuum strategy has fostered an emphasis on specialized facilities and congregate settings.

Community Service Patterns: Changing But Delivering Confusing Messages

From neighborhoods in cities to rural communities, the citizens of Ohio have seen people with developmental disabilities become much more visible in their lives during the past 25 years. A definitive study of the attitudes and actions of the citizenry in response to this presence is not available, but the authors of this Paper have made a point regularly to talk with and survey a wide range of citizens from a variety of communities during this period of change. One conclusion from those conversations is that, as much as people have become accustomed to and mostly accepting of shopping, worshiping, and living alongside people with disabilities, only a few Ohio citizens are enjoying individual relationships of mutual support with people labeled as developmentally disabled. The majority, whose lives are absent of such relationships, have their view of the "people with developmental disabilities" brought to them mostly by the actions of community-based service programs.

The Importance of Relationships With Other People

At the present time, most planning with and for people who have developmental disabilities focuses on making sure that each person has a good place to live (residential services) and something useful to do during her/his daytimes (education or adult services). Service-providers, planners, and families have, however, begun to learn, from their experience with the people themselves and with the delivery of services, that what had earlier been thought of as extras— especially supports for lives enriched by relationships —often turn out to be what makes the difference between success and failure, between lively participation in community life and continued isolation. Paying attention to making and keeping-up relationships is a most important part of planning with each individual who has a developmental disability.

Most people count on their connections to other people as the significant source of stability, security, and richness in their lives. How important are these relationships? They are so important that most of the culture's social customs and ceremonies have something to do with the beginning, maintenance, or ending of a connection with other people. Examples include weddings, funerals, christenings, and major holidays when families gather. Even the Super Bowl has become a traditional occasion for friends to be together.

Most people prize their friends and wish they could do better for or by them. Whole industries are devoted to enabling people to better meet others (e.g., catering services, party or convention organizers) or to more easily express closeness to others (e.g., the greeting-card business). The lives of most ordinary citizens are relationship-filled, at least compared to the lives of the majority of people who have developmental disabilities. One of the major facts of life for most people with disabilities is that they often have <u>few</u> connections to other people—few, if any, close relationships with others. Consider some examples about what is going on:

Most people count on their connections to other people as the significant source of stability, security, and richness in their lives.

- For nearly twenty years there has been a steadily strengthening effort, across North America, to make it possible for children with disabilities to go to school in the same places (school buildings, classrooms, etc.) as other children. Underlying this effort has been the belief that something as simple as joint presence in the same spaces would be the key to integration—that *being together* would, somewhat automatically, lead to *being friends.* To some extent, this belief has been justified, but children, parents, and school personnel have come to realize that things are not always so easy. One commentator about this observed:

> With the integration of children with challenging needs well established in our...school system, the need for social integration has never been more apparent. Our youngsters have moved through the system and have experienced first hand what it's like to be one of the crowd and to be included in all school-time activities. But at 3:15 p.m., like Cinderella's coach and dream at midnight, it all ends, not to begin again until 9:00 a.m. the next day. Weekends and holidays are lonely times and the longing to do what other teens are doing increases.[4]

- In the last ten years, lots of people with developmental disabilities have been helped to find and keep better jobs because of the growth of supported employment and other associated ideas and practices. Again, early on, it was expected that supported work would, somewhat automatically, help workers with disabilities toward making connections with fellow-workers—connections that would enrich the lives of all. Again, to some extent what was expected to happen has happened, but students of supported work programs have observed that:

> ...the majority of contact (at work) between nondisabled employees and supported employees concentrated on task performance; very little contact between employees was reported during breaks at work and after work hours.[5]

- The likelihood that someone with a developmental disability will establish a relationship or even a first-name acquaintance with a local shopkeeper or bank teller is greater if that person enters the community as an individual, rather than as a member of a group. Most people notice groups of 3-10 people with developmental disabilities shopping, eating in a restaurant, or attending a community event. Each group member is, then, likely to be identified by the group's label and not as a neighbor or a fellow citizen. The overall effect generally is to generate a range of undesired emotions from pity, fear, and uncomfortableness.

- Those who have helped people with developmental disabilities make plans for improved future lives (e.g., through methods like Personal Futures Planning) have noticed that, when they ask someone with a disability and her/his family about "who is close?", the responses overwhelmingly include: a) immediate family members, b) other people with disabilities [6], and c) paid staff of human service agencies. It is rare that the social network of a person with developmental disabilities includes very many people who are there only because they know and like the person and, therefore, want to be a part of the person's world.

Only a few Ohio citizens are enjoying individual relationships of mutual support with people labeled as developmentally disabled.

- Observers in large "residential facilities" where lots of people with developmental disabilities live have noted that sometimes days or even weeks can go by without a single outside visitor for even one person who lives there.

- John McKnight, a well-known critic of human service processes, has observed:

> ...if one were to say to the average citizen, "I want you to take five men and buy a house in a neighborhood in a little town where those men can live for ten years. And then I want you to be sure that they are unrelated in any significant way to their neighbors, that they will have no friends, and that they will be involved in none of the associational or social life in this town," I think that almost every citizen would say that this is an impossible task.
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> Nonetheless, ... it has become clear to me that systems of human service... have managed to achieve what most citizens would believe impossible—the isolation of labeled people from community life even though they are embedded in a typical home in a friendly neighborhood in an average town.[7]

Given how important relationships with others are to people in general (most current novels or commercial films are about relationships between/ among people—both how vital and how difficult they often are), this lack of interpersonal connections in the lives of people with developmental disabilities is troubling. This is especially so in view of the observation that relationships for people may actually be hindered or even prevented by many current practices of human service agencies. For example, the often-bemoaned turnover of workers, particularly in so-called "direct care" positions (i.e., those jobs where workers have the most personal contact with, and possibly the most power/influence over, people with developmental disabilities) means that the faces around people with disabilities tend to change constantly. This often happens without any announcement to or preparation of the person with disabilities, who may find her/himself suddenly without someone on whom she/he had grown (or been forced) to depend—for service, for guidance, or even for just plain human contact.

Confusing Messages of Community Service Programs

New service approaches are developing in some Ohio communities, and it is in those places where one is most likely to find people with developmental disabilities living in the midst of family, friends, and the general citizenry in a manner that is enriching and security building. Otherwise, Ohio citizens are getting a rather confused message from the service system that has been set up to support people with developmental disabilities.

People with developmental disabilities placed in these facilities are, however, still living with groups of unrelated adults who were collected by the organization that has the legal claim on the facility.

By examining the experience of people with disabilities from several perspectives—families, schools, places of residence, places of work, relationships with other people—this pattern of confused, or at best mixed, messages about people with developmental disabilities is revealed.

In Families... To be celebrated is the fact that most children with developmental disabilities in Ohio now live with their families or with substitute families. Families who are rearing their children now may be more assertive in their demands for a range of choices for their children, to pursue those choices, and often to create them because their absence. Help for families of young children has become more available during the last few years. With the active help of local "Early Intervention Collaboratives" about 75% of Ohio's County Boards of MR/DD have developed early childhood programs that begin to make integration a real experience for children with developmental disabilities.[8] In addition, Ohio's "Individual Options, Home and Community Based Care Waiver" and "Supported Living Program" have begun to pay for supports in a child's home.

The celebration is constrained, however, by the continuing practice of placing children in institutions, nursing facilities and specialized group homes. There appears to be a continued reliance on these options by the courts and human service officials in our state, especially when a child's circumstance is particularly challenging.

In Schools... Typically people with developmental disabilities in Ohio have their life-experiences decided by the fact that they have a disability-label. A close look at the big picture shows that many children with developmental disabilities in the state do not experience school with children who do not share that designation. Although today children with developmental disabilities in Ohio are increasingly attending public schools, they seldom sit in the same classrooms with other children. As well, 85 of the state's 88 County Boards of Mental Retardation and Developmental Disabilities still operate segregated school-age programs for children in locations entirely separate from local public schools. Although individualized educational plans are required by law for all children with disabilities, solutions for most are placements in classrooms with groups of other children who carry disability labels.

In Places of Residence... Very often people with developmental disabilities live only with other people who are also so described. Adults with developmental disabilities are much less likely to live in institutions than they were 20 years ago, but they are almost as likely to live in such places as they were five years ago. Many communities want to change patterns of institutional living, but success has been slowed by the development of community-based institutions that evolved out of the community living movement of the past 25 years. That movement closed some institutions and released thousands of citizens who had been sent away from their homes, but it also created whole new sets of buildings and practices that continue to keep people with developmental disabilities apart from typical citizens. While the 1970's and early 1980's were times of great movement out of state-operated institutions, today most developmental centers[9] in Ohio have undertaken new construction to replace antiquated buildings for the remaining 2,500 citizens who make their homes there.

It appears that approximately half of the adults with developmental disabilities[10] in Ohio remain with their families or in other situations where no paid residential service is utilized, while the other half are reliant on facilities or paid-for residential services to make their home. The customary number of people grouped in many of these these facilities has reduced over the past several years; this has occurred because of changes in policies by funders and licensers of facilities. People with developmental disabilities placed in these facilities are, however, still living with groups of unrelated adults who were

All of these non-building options signal a hopeful sign of change, but they represent a small fraction of the output of taxpayers dollars to support people with disabilities.

collected by the organization that has the legal claim on the facility. The majority of these facilities are physically located in municipalities, many in residential neighborhoods. Ohio Department of MR/DD officials say the norm is for people to live in groups of five to eight, depending on the facility's funding source, but that larger facilities of between 36 residents and over 100 residents are counted as "community facilities". Several dozen of these exist throughout the state.

To describe people's life experiences in any group residential facility in this state is difficult. There is much variety in a system that is mostly privately operated. It is safe to say that most facilities provide residents with some level of contact with community activity (shopping, restaurants, etc.), but that people experience most of that activity in groups—on "outings"—rather than as individuals. Shift patterns of staffing are common in these facilities. "Homes" are less than homelike. Facilities funded under the ICF/MR funding stream are particularly oriented to routine, regulation and control by the medical/professional field. Some people do live in apartments and houses that are more in their control than in the control of a residential service organization, but over 1,800 persons with developmental disabilities live in Ohio's nursing homes, giving Ohio the largest number of such placements in the United States. It is hard to imagine that residential services in Ohio provide the control, comfort, privacy, and well-being that most citizens derive from their own homes.

On a more hopeful note, a growing number of Ohioans are now taking advantage of state funds, which became available in 1990, that are designed to support their individual plans to live good lives in the community. These funds, called "Supported Living" funds, are flexible and locally controlled so that individually tailored adaptations, services and resources may be purchased, thus allowing a person to make a home of her/his own. It is too early to tell whether Supported Living funds will actually do what is expected of them or whether they will be siphoned off to support existing professional therapies and, thus, end up having a minimal impact on a person's ability to live successfully in the community.

Also made available to Ohio's families in the last decade have been "Family Resources" funds. These will pay for respite, physical adaptations, equipment, and other forms of assistance that allow a person to remain in his/her natural family home. Medicaid Waiver funds have also begun to provide support to individuals making homes in natural settings. All of these non-building options signal a hopeful sign of change, but they represent a small fraction of the output of taxpayers dollars to support people with disabilities. Control of these dollars (Family Resources and Supported Living) rests with County Boards of Mental Retardation/Developmental Disabilities whose histories and resources are highly tied to facility-oriented and group approaches to meeting people's needs. For the most part, these newer options appear to be highly susceptible to bureaucratic program structures in the local agencies that manage them. They may come to be used more to supply what an agency needs than what individuals desire. Given current economic times, their potential for growth mostly rests with a concurrent ability on the part of agencies to undo other building-oriented programs. That may prove difficult, because many of the buildings were paid for with funds from state-issued bonds. The debt represented by those bonds is far from retired, and current state policy insists that the buildings must be used for programs for people with developmental disabilities until the debt is paid.

Most people with developmental disabilities in Ohio still experience lives that are separated from the general population by the services they rely upon, including schools, sheltered workshops, residential services, and others.

In Places of Work and Daily Activity... People with developmental disabilities still do not work in many places where there are other workers without a disability label. About 67% of 22,111 adults with developmental disabilities identified by the state's County Boards of Mental Retardation/Developmental Disabilities in their communities attend sheltered workshops or adult activity centers on a full-time basis. Another 13% of those adults spend part of their days in County facilities while working elsewhere the other part of the time. 4% of adults are, reportedly, retired. About 2% of adults receive supported services in their homes, and the status of another 3% is unknown. One (1) per cent of reported adults are in "evaluation". This leaves 10% of reported people spending their days in work settings in the local community—some in "industry-based employment", some in "competitive employment", and others (about 3% of the total, or 649 people) in "supported employment".[11]

Many other people with developmental disabilities spend their days in programs that are similar to County Board workshops but operated and funded by other agencies. Examples include programs offered by organizations like Goodwill Industries.

Spending days in such facilities shelters people from a life of collaboration and affiliation with typical and valued citizens. The experiences inside such facilities vary from serious work in some instances, to so-called "training" in nearly every facet of life imaginable (sexuality, cooking, work skills, problem solving, etc.). The ability of such community institutions to prepare people for work and life in the real world is questionable, especially given the understanding that a major obstacle to learning faced by many people with developmental disabilities is the difficulty they have in transferring (or generalizing) what they learn from one place to another. The actual track record of these facilities at preparing people with developmental disabilities for real life is worse. Sheltered workshops and activity centers are, at their best, segregated places for people to work and socialize. In many cases, though, workshops serve the actual function of an adult day care or day room for the community. They cannot offer wages that lead to a more financially independent lifestyle. They are commonly plagued with problems of down-time when contract work runs out, and they typically are multi-purposed in program design (e.g. habilitation programs, vocational training, real work). This causes both service recipients and staff to be confused about a program's purpose.

In some counties efforts by the County Board of MR/DD are underway to assist and support people with developmental disabilities to find real employment, one person and one job at a time. Additionally, the Ohio Rehabilitation Services Commission has, over the past several years, devoted more attention and more resources to trying to help people get jobs outside of facilities. The success of such efforts has been limited, however, as the above statistics demonstrate. The financial incentives for seeking "supported employment" for people with developmental disabilities are weak, and they tend to be overpowered by incentives to maintain the facility-oriented system as long as possible. Bureaucracies are more paralyzed than they are flexible. They find it hard to pursue the things that people with developmental disabilities might choose because what already exists in buildings, debt, and long-standing organizations are what the bureaucracies are best at offering. It is worth asking whether, if things could start over from square one, our communities would spend the money differently on the second time around.

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A Last Word about The Way Things Stand Now

The analysis in this Paper has argued that the lives of most people with developmental disabilities in Ohio and their families are highly influenced by the service system on which they rely. Such an argument leads to the conclusion that the lives of people with developmental disabilities are closely tied to facilities and programs that separate them and group them away from their fellow citizens, even though they may in a technical sense be physically present in their communities. Most people with developmental disabilities in Ohio still experience lives that are separated from the general population by the services they rely upon, including schools, sheltered workshops, residential services, and others. In most of these services:

- people's choices are limited and controlled
- the integrity and social status of the individual is diminished in the eye of the community
- resources available to typical citizens are replaced by resources aimed at treating a person's deficits
- people become clients first, while their roles as workers, students, or citizens become secondary; people become dependent on a specialized/separate world for their well-being
- the relationships people have are mostly with others who also have disabilities or with people who are paid to spend time with them

Minority efforts exist in many of our communities, and these show hope of growing in the coming years into back-ups and supports for people who are building productive and satisfying lives. There are a number of stories about Ohio citizens with developmental disabilities whose lives have improved dramatically over the past several years. Some children with developmental disabilities are starting their lives in ways that any child would be expected to start her/his life, planting seeds for a productive and useful adulthood. It would be hard to distinguish the life stories of a few people with developmental disabilities from those of typical citizens, other than by the forms of help that have been necessary to allow them to be together with family, community and society. There truly are stories in our schools, churches, neighborhoods, and workplaces about people with disabilities who are no longer excluded. These people share their gifts, talents and challenges with their fellow citizens. They serve as examples for the future and for individuals and their families who are working for better lives in the midst of our American culture. As one storekeeper in an Ohio community said, "I've started to get to know a couple of people (with developmental disabilities) that shop here. I can see how silly and wasteful it is to keep them away from everybody else. It has not been fair to me or to them."

There is a monumental challenge before Ohioans—to undo many years of work that have resulted, much to the dismay of many, in the construction of rigid and often counterproductive human services. The pattern left by much of that work needs to be undone because it leaves most people with developmental disabilities and those closest to them powerless to put the resources designed to support them to use in ways that bring to them the benefits of living with others in the midst of community life.

Chapter Three. The Way Things Could Go

Assumptions

The word, assumption, means an idea that is taken for granted or treated as if it were a proven fact. A statement of assumptions helps define a way of thinking about people with developmental disabilities and about the role of supports and services in the lives of such people and their allies. These assumptions have to do with the place, the status in our day-to-day life of people who have been marked by society because they have developmental disabilities (or the place of people who have been otherwise labeled in negative ways).

Assumptions that will help Ohio leave its history behind:

- Persons who are marked because they have developmental disabilities are in jeopardy of having other people use customs, authority, wealth, and power to establish or keep people with disabilities in positions of low status and power throughout their lifetimes.

- If someone with a developmental disability is to enjoy a life of respect with others and get useful help in ways she/he chooses, it will take the deliberate attention and focused hard work of other people. This will have to happen in a variety of ways throughout the person's lifetime.

- Justice is difficult to attain for those who are marked by poverty, disability, age, race, gender, or religious affiliation—unless the people carrying those labels enjoy enduring associations with people who are valued and,therefore, powerful. There don't seem to be any real substitutes for the strength and security that come from family, kinship, and alliance with others.

- Useful help comes much more often from those who know someone well than from those who are strangers to that person. Personal knowledge makes help more relevant. In fact, helping can be a natural interaction between people who know each other well and who share time and space in daily life. When help comes to someone from an agency or organization, the likelihood that the served person will be personally well-known to and regarded as <u>the</u> most important by the agency is reduced if not lost. Given the marks that are noticed by others in people with developmental disabilities and the resultant jeopardy those people face, the task of safeguarding the dignity and humanity of each person as he/she is helped by services remains a vital task.

- The human capacity to grow, in a variety of ways throughout life, is aided and supported—nourished in large part—through relationships with other people. The alliances that come from loving, respectful relationships with family, friends, and associates provide a basis for personal security.

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Most people seem to understand that alliances with others are sources of strength. People intentionally join with others around

common interests, places, routines, and beliefs. They join together to accomplish things that could not have been achieved by anyone singly. There is power in collective participation and action that helps define the political and social world in which we live. Groups of people who share a coherent set of ideals or aspirations can accomplish complex and challenging tasks and can sustain the effort to completion even if the task is lifelong.

This power of affiliation and alliance in our political and social world wears at least two faces. When one is on the inside, security and well-being are nearly automatic. If one is outside the power alliance, one can be routinely oppressed and made to suffer the indignities and loss of experience and opportunity that seem to go along with segregation, prejudice, and alienation.

Those most at risk of such alienation seem to be people who are marked by others as different in some negative way. It does not matter whether the marking is a conscious act. People with developmental disabilities are so "marked".

Planning Principles

The above assumptions help define the most important concerns about people with developmental disabilities and the supports and services that are organized to assist them. The following planning principles help describe strategies that can improve the future status and experience of people with developmental disabilities in the human service world. Among other things, these principles imply that if people with developmental disabilities are going to really experience community membership and citizenship there will have to be a change in the way help for those people is organized now. This must be a change in the power exercised in human services by people with developmental disabilities and by their allies, which implies a change in the roles carried out by human service workers.

For a long time, people with developmental disabilities have been underestimated. The society and its structures have often taught people with developmental disabilities and their families (or other personal allies) to be completely dependent upon human services and professional personnel. Thus, people with developmental disabilities have been converted into clients, and many more people without disabilities have become planners and managers of these clients' experiences.

This must be a change in the power exercised in human services by people with developmental disabilities and by their allies, which implies a change in the roles carried out by human service workers.

These planning principles are offered so that those who read this Paper can consider moving away from clienthood as the chief role for people with developmental disabilities within human services. The planning principles are organized around three topics: 1) the importance of someone's PERSONAL EXPERIENCE as a source of planning information; 2) the necessity for PERSON-GUIDED structures and methods; and 3) the impact of LEADERSHIP in efforts to achieve SOCIAL JUSTICE.

The importance of someone's personal experience as a source of planning information.

This first principle is a reminder that most of the information that is needed to plan with a person with developmental disabilities is available from that person or from his/her friends and allies. This principle should be relied upon by human service organizations that want to be useful to people. The idea that people are (or can be, with the help of those close to them) experts about their own preferences, interests, and hopes is sensible. It is an idea that fits with the developmental assumption that all people have the capacity to learn and change throughout life.

As noted above, people with developmental disabilities have, in the past, been taught to approach and respond to the human service world as clients. They and their allies have learned to seek solutions from organizations with specially-trained, certified personnel. This has happened because the focus of planning for people with developmental disabilities has centered on their differentness from others, rather than on all the needs and characteristics they share jointly with other community members. An approach to helping that counts on people's personal experience as primary information contradicts the tendency to make people into clients. It presumes that solutions that are designed for people in the absence of a knowledge of their experience could rarely, if ever, be relevant or fully responsive to a specific person.

Reliance on someone's personal experience as the major source of information for planning highlights the critical importance of each person's history, which contains the seeds for an understanding of: a) those experiences that have occurred that ought not to be permitted to occur again, and b) experiences that are high points in a person's life and that offer clues to their dreams and the possibilities for their futures.

The necessity for person-guided structures and methods.

The first planning principle leads to the second, which is meant to get helping organizations to pay attention to how they are structured and how they operate. Does an agency affirm the value of first-hand information from each person helped? Does the organization use this first-hand information to shape what it does—how it offers its services? The answers to these questions, in any organization, will affect the roles that people with developmental disabilities and their allies are allowed to play within the organization. Clearly, what is necessary is that those roles become more powerful ones.

Unless an organization decides to be guided by the situations of individual people who need assistance, and works hard to live out that decision, the distractions of managing an agency in a political context will usually prevail.

Nearly all current human service organizations are hierarchic in structure. That means that the power inside these organizations—power for decision-making, for choosing how resources are used, for selecting a mission, for developing operational practices—rests with people who may be distant from the people the organizations intend to help. Power is often held and exercised by people who don't know much about the daily experience of specific people with developmental disabilities. While this way of organizing—hierarchy—may be useful in the technical or corporate world (because, at least theoretically, it contributes to efficiency), its merit in the world of service to individuals with developmental disabilities seems more and more questionable.

The earlier assumption that the most useful help to someone comes from those who know that person best makes it obvious that distance between the most influential people within a helping organization and the people who are to be helped is a serious problem. One consequence of this distance is that the work of an agency, or even its mission, gradually can get shaped more by the demands of the organization, by politics or by funding patterns, than by the experiences and wants of the people to be helped. Unless an organization decides to be guided by the situations of individual people who need assistance, and works hard to live out that decision, the distractions of managing an agency in a political context will usually prevail.

There are indicators that tell whether a helping organization is person-guided. One of these is the manner in which help for people with developmental disabilities is organized within the agency. For example, a common manner for offering people with developmental disabilities places to live has been to group people who do not know each other together in households. From the view point of each person this procedure makes little sense. It is worthwhile asking what distractions or political constraints would lead to the belief that putting strangers together in houses is a sensible practice. If assistance to people with developmental disabilities is organized in such a way that it results in those people's daily experience being a lot different from the experience of other citizens (who, for example, usually don't live with strangers), then the agency that does this is not person-guided.

Another indicator of whether an organization is person-guided is to be found in the planning procedures that the organization uses. Do the goals, objectives and plans of the organization show that the needs, preferences, and satisfaction of people with developmental disabilities have been the major sources of information? Does the pattern of the organization's use of resources match the kinds of help that people with developmental disabilities and their allies ask for? If, for example, people want and need dignified, paid work and the organization uses a large share of its resources to offer them rote practice at things like counting coins, it is reasonable to conclude that the organization is not person-guided.

Perhaps the clearest way to test the position of people with developmental disabilities in an organization's life is to look carefully at the kinds of decisions that are theirs to make. Someone who is interested in a particular organization could test that organization by asking such questions as:

- Does the organization arrange things so that people with developmental disabilities and those closest to them make those choices that they are likely to make best? For example, do people have a chance to choose with whom they will spend time?

- In the instance of arranging places to live for people, do people have the chance to make the most meaningful choice—the choice about with whom they will live? What about choices about daily schedules, about who gets to come to visit and when, about who the assistants will be and when they will be there?

People with developmental disabilities, members of their families, and their allies need to assume (or reassume) positions as leaders of the effort to design the forms of assistance that will best support people in community life.

- Does each person with developmental disabilities have a major voice in what becomes part of her or his personal plans, including those official plans maintained by the organization?

An organization that struggles to make room for this kind of decision-making by people with developmental disabilities is person-guided. It is an organization that relies on the preferences and wishes of those who receive its help as it decides about its operating structures and practices.

The impact of leadership in efforts to achieve social justice.

One of the working assumptions of the Community Living Paper is that people with developmental disabilities are subject, from early in their lives, to having their differentness both noticed and negatively valued by others. The receipt of this value judgment leads to an imposed reliance on separate, disability-specific, and professionalized forms of help. Being noticed leads to the status we have called clienthood. This pattern has been relentless in people's lives. It needs to change. One avenue toward change is an expanded understanding of what "leadership" means.

As already noted, people with developmental disabilities and their allies are quite capable of telling others about their interests, needs, and dreams. They are likely, however, to lack experience at doing this. They have been, after all, regarded as people who need to be told things, rather than as the tellers. People with developmental disabilities, members of their families, and their allies need to assume (or re-assume) positions as leaders of the effort to design the forms of assistance that will best support people in community life.

John O'Brien and Connie Lyle distinguish among different leadership styles by contrasting different descriptions of "power". They do this by borrowing from the earlier writing of Starhawk about the distinctions among *power-over, power-with,* and *power-from-within.*

> - *Power-over* other people arises from the ability and willingness to make decisions for others and to enforce their compliance by authoritative control of rewards and punishments.
>
> - *Power-with* other people arises from people's ability and willingness to listen to and be influenced by another's perceptions and suggestions and to offer their perceptions and suggestions in turn.
>
> - *Power-from-within* arises from a person's willingness and ability to discover and creatively express the abilities and concerns that they find spiritually meaningful.... Power-from-within gives a person courage to act when important values are threatened, even if the short-term prospects for success are poor.[12]

The process of helping people with developmental disabilities and their allies gain in authority and confidence requires a way of leading that relies more on *power-with* and *power-from-within* than on more customary leadership styles.

Helpful leadership includes roles like that of encourager, supporter, or facilitator. Good leaders become willing sharers of both resources and power.

Helpful leadership includes roles like that of encourager, supporter, or facilitator. Good leaders become willing sharers of both resources and power. Helping others have more control over their own lives and futures means giving up leadership styles that are directive or controlling (e.g., facility-managing styles). Given that the rewards for leadership have, in human services, for so long been tied to administration and to demonstrations of authority, this change will not be an easy one.

There Is A New Tomorrow That Exists Today: Images of Life in Community

Development of the kinds of connections necessary to help shape desirable futures for people with developmental disabilities (as well as those of the organizations that offer them service) requires attention and activity in the places where people live. There are localities in Ohio where efforts have focused on supporting people with developmental disabilities as they take on the status of citizens of their communities. In those places, everyone involved in offering that support has experienced change in his or her life. Often this change has begun with a process of re-thinking or clarifying ideas about what life in the community is like when that life is described as "good". Wendell Berry offers guidance about the meaning of "good".

> A good community insures itself by trust, by good faith and good will, by mutual help. It depends on itself for many of its essential needs and is shaped from the inside. When a community loses its memory, its members no longer know one another. How can people know each other if they never know one another's stories? If people don't know the story, how to know whether to trust? People who don't trust one another do not help one another, and moreover fear one another.[17]

When life has changed in desirable ways for people with disabilities, their allies, and others involved with them, strategies of collaboration and trust most often prevail. People invest in knowing one another well—in knowing the stories of others and in sharing their own. People with developmental disabilities are present as a natural, if heretofore excluded and often underestimated, part of family and neighborhood life. They are welcomed and supported as active participants in the process of shaping the futures people expect to experience together.

When life has changed in desirable ways for people with disabilities, their allies, and others involved with them, strategies of collaboration and trust most often prevail. People invest in knowing one another well—in knowing the stories of others and in sharing their own.

Life in a good community is full of images, stories, examples, and signs that many people recognize and agree about. Many of these signs are small, rather ordinary events. Some signs of community—events that people sometimes take for granted—might include:

- standing with your nose pressed against the glass that separates you from your newborn son; not knowing if his future is measured in hours or years; having a woman you've passed in the hallway but never met come and stand next to you and quietly introduce you to her son; listening to her deliver her message in just a few words: "I could have taken him home in a shoe box, he was so tiny; raising him has made a brave woman of me."

- being three-and-a-half and having your pre-school teacher think that you are absolutely irreplaceable; and being the one child in the class who has a severe disability.

- getting to ride the same bus to school with your brother, now that there's a lift on the bus.

- listening to your niece recite poetry she's learned in pre-school class, and knowing that, when she was born, she had conditions that were considered severely disabling.

- sharing an ice cream cone with your dad on the way home from a ball game.

- watching your son walk across the high school stage on graduation night, just as all the other graduates have done, knowing that his "autism" hasn't gone away, but celebrating the fine young man he is becoming.

- getting your first apartment at 21 with a kid you went to high school with—you were the kid in the "multiply handicapped" class; he was the volunteer from the honors program.

- using your electric wheelchair to be an usher at church on Sundays.

- being a teenager who has 4 high school band "letters," a President's physical fitness medal, is elected to the homecoming court, and who has Down's Syndrome.

- going to visit your grandparents and having them let you know that your visit is part of what makes life beautiful for them.

- living in your own home even though the seizures haven't stopped; getting the help you want and need from people you select and who come when you decide they should.

- feeling confident enough about yourself and your parents to let them know, at age 22 (and having a developmental disability), that home would be a little better if it were <u>your</u> home; having them take you seriously and begin to plan with you to make that possible.

- listening to a friend tell her favorite story over and over again, and hearing something each time; knowing that for her to risk asking you to listen again is a sign of her capacity to trust in you.

- remembering the person you credit with first teaching you to play basketball; being friends with that person long enough that you're taller than him now; knowing that when you first met and he gave you those first lessons he lived in a big institution.

- having Sunday brunch at a friend's house nearly every Sunday for a couple of years so you can visit, have someone else do the cooking, play with the kids, and do your laundry without spending any money.

- starting a fix-it repair service with your uncle whom you didn't meet until you came home from the institution after 25 years.

- having your co-workers throw a surprise birthday party for you after you all "clock out" for the night.

- delivering the eulogy at the funeral of a young man who died before his dreams came true.

- always having the coffee pot on because people stop in often to visit.

- going to the local tavern on St. Patrick's Day to enjoy the music and the celebration.

- sharing dinner together and making a party out of washing the dishes.

- having your friends from the church and your family organize a schedule so that you can recover from surgery at home, not in the nursing home.

- sharing your home with a friend for six years now after living in institutional places for more than 20 years.

- sitting around looking at photos with a few friends, and telling, listening to, and remembering the stories.

- being invited to share a favorite story with the children in the first grade class, and being asked back on a regular basis.

- taking supper to the neighbors who have just lost their grandfather.

- looking for work, managing a challenging insulin injection procedure for yourself pretty much on your own; taking care of the house when your family is away; and having mental retardation.

- having your neighbor stop over because he missed seeing you out this morning.

- having a couple of friends volunteer to help take the old wallpaper off and put up new.

- treating a friend to lunch because you want to share a little of your winnings from the raffle that you won at the local high school football game last week

- helping put a roof on your neighbor's house, even though you've never done anything like that before.

- keeping in touch with a friend who is away.

- knowing your newspaper carrier by name, and having her know yours.

- being forgiven for failing a friend because you forgot a promise you had made and intended to keep.

- having a laugh with friends in an up-scale restaurant, when you're served redskin potatoes that have been sculpted to look like giant mushrooms.

- taking your turn at the microphone during the annual community concert in the park; having the children gather around you afterwards to show them how you play the spoons.

- neighbors and friends starting a scholarship fund in honor of a beloved teacher and coach who died before others expected him to.

- sitting on a front porch on a street full of front porches, chatting softly with your neighbor on a summer night.

- writing letters to the editor and articles for the local newspaper.

- looking up a phone number and calling a friend with the good news that you've moved into your own place, after never "succeeding" in the telephone-program you worked on for years in the group home; finally having something worth using the phone for.

- getting a job for someone who has been waiting for a chance to have full-time work.

- visiting the same campground on the same weekend every summer so that you can visit with the family you befriended on your first trip there five years ago.

- being patiently tutored in gardening by your 76 year old neighbor, hoping that the lessons will continue for years because some things, happily, take a long time to learn.

- hosting the annual Christmas party for the housing association you belong to; being a part of creating and keeping traditions.

- getting to hold and rock to sleep your neighbor's grandchildren when they come to visit, even though some people still treat you as a dangerous person.

These are ordinary things—everyday events. They are examples of the rich pleasure and pain that accompany people living together in community. In their simplicity and variety these ordinary things represent the kinds of experiences that people with developmental disabilities will increasingly come to have, as the vision of community living becomes more and more real for them.

Expanding The Boundaries of Community Membership Carries Implications and Tensions

Substantial change in the ways support and service is structured by helping agencies is an essential part of accomplishing desirable community living for anyone with a developmental disability. As organizations change, communities will change as well. Those organizations are, after all, part of the fabric of their communities. The pace of change and the ways both communities and organizations change will vary because they will reflect the diversity of geography, history, service and community traditions, and economic circumstance that is represented by Ohio towns, cities, and rural neighborhoods. It is possible, however, to anticipate many of the tensions and issues that would emerge as human service organizations begin to reshape their approaches and roles in assisting people with developmental disabilities. What follows is an attempt to describe some of those issues, first as they affect human service organizations and then as they affect communities at large.

Implications of Change for Organizations:

•Honoring the rightful place of people with disabilities and their allies in deciding about what constitutes useful support and help will mean diminishing the power currently held by professional decision makers.

•Safeguarding the integrity of individual choice implies that a reasonable number of acceptable service and support options exist from which people with developmental disabilities and their allies may select. It is not good enough for a person to be presented with only one real option; choice involves a selection among genuine alternatives.

•Avoiding the continuation of separate-but-equal program designs implies an inclusive philosophy that is not a part of service tradition. There will have to be a reduction in the use of separate facilities and congregate program sites that now consume most of the money allocated to assistance for people with disabilities. Among other things, this will mean avoiding financing for buildings that depends on program use for long periods of time (e.g., financing through bonds, which has been a common way of paying for segregated buildings in Ohio).

•Extending the inclusive approach to education means finding ways to ensure that all children in a community have an opportunity to learn together in schools, in classrooms, and in other places in the community.

Finding ways to shift increasing shares of resources, which are intended to help people with developmental disabilities, from the control of service agencies to control by people with disabilities themselves and their allies will be a necessity.

•Finding ways to shift increasing shares of resources, which are intended to help people with developmental disabilities, from the control of service agencies to control by people with disabilities themselves and their allies will be a necessity. This will require both the development of the necessary fiscal means and the removal of many barriers that now stand in the way (e.g., the likelihood of cash assistance for needed supports being "deemed" as income by welfare administrations).

•Recognizing the importance of each person's reputation and status in her/

his respective community will require re-thinking the ways in which people are grouped, interpreted through program structures and practices, and imaged in fund-raising. Citizenship carries with it a different status than does clienthood, and that status needs to be confirmed through the ways that people are portrayed.

- Supporting and honoring the integrity of families means returning to them the fundamental role of being representatives of their (minor) children. Redefining the professional role as secondary to family means re-working procedures, program assumptions, and professional identities as experts/specialists.

- Organizing assistance to people in ways that promote personal alliances between people with developmental disabilities and local citizens, rather than in ways that perpetuate stereotypes and distance, challenges long-standing human service practices.

Specific implications for how organizations structure or make plans for themselves:

- The human service world will be required to renounce the myth of segregation—e.g., the notion that segregation is "...for their own good."

- Agencies, including public schools, will assume a more regular posture of deferring to families' wishes and hopes for their own children.

- Agency planning will reflect an absence of congregate solutions in terms of housing, work, etc.—so that patterns of segregation are eliminated.

- The disappearance of certain service styles (e.g., segregated schools, institutions) will add stress to organizations and to the system—stress that arises: from the need to re-train and re-assign staff, from the requirement to help find new uses for obsolete buildings, or from the inability, any longer, to solve problems by moving people with disabilities somewhere else.

- Agencies will organize themselves so that there is an array of useful service options available for people to purchase.

- Accountability may be more clearly related to the experiences, <u>now</u>, of people with developmental disabilities. Increasingly, service workers will be held accountable for the quality of their work by the people to whom they offer assistance, as those people gain in practice and confidence about making decisions for themselves.

- There will be a need for determining more appropriate roles that organizations can play as people with developmental disabilities assume greater control in making their own decisions. Fewer human service jobs of the kind that people are accustomed to now will exist, but there may be more actual work to be done to help people with developmental disabilities.

Citizenship carries with it a different status than does clienthood, and that status needs to be confirmed through the ways that people are portrayed.

- Paid services will add depth and support to less formally organized help; for many people with developmental disabilities, paid service workers will only offer back-ups to assistance that is regularly received from a person's friends and allies.

- Contract positions and/or part-time, small-scale, personal responses will replace life-long career positions for many professionals.

- Human services will use money in a different way. It is unlikely that expenditures (from taxes) for help to people with developmental disabilities will decrease, but the pattern of those expenditures will change drastically (e.g., much less centralized control of funds; much more control at the local level and within the direct influence of people with disabilities and their allies).

- MR/DD agencies will no longer be involved in their traditional ways of functioning in the real estate market (i.e., buying properties themselves and then "placing" people in them, either to live or to work).

- Control of services and systems (also of planning, staff selection, policy development) will be closer to the people who use services.

- There will be lots more thoughtfulness about growth of agencies, e.g., what unlimited growth or increase in an organization's size beyond a manageable scope would mean.

Specific implications for how human service organizations interpret people with developmental disabilities to their communities:

- Agencies will cooperate with (but not try to control) organized efforts to promote relationships between people with developmental disabilities and people who don't have such disabilities.

- People with developmental disabilities will be interpreted as valuable members of their communities.

- Professional identities will change from that of "specialists for special people" to that of "useful assistant" to people:
  - -fewer signs of status difference
  - -less predictability about job responsibilities
  - -more rewarding work

- Informed choice is usually based on experience; people trying things out ought to be expected; helping organizations will be required to build flexibility into their structures.

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- There will be shifts in human service worker and organizational roles to more functional help as defined by a specific person and her/his allies.

- Integrated work places will replace segregated vocational services.

- Separate schools will cease to exist. Other (non-segregating) uses will be found for current buildings housing these programs.

- Decisions about grouping of people will be made on a basis other than the labels that are assigned to people.

- Services will search for ways to identify common interests of labeled and non-labeled children and to create opportunities to bring children together.

- Residential institutions (public and private) will fade away. They will no longer be service options.

- Temporary placement (fostering) of children with developmental disabilities will decrease as adoptive options increase.

- Professional helping strategies will change. Human service personnel will become personal and planning assistants, offering people guidance about community life, rather than being diagnosticians or prescribers of units-of-service.

Implications for Communities

- The challenge of an emerging inclusive social policy requires an identification of and with the people who have been excluded or kept separate; finding ways to meet the needs of shelter, schooling, work, and social opportunity without labeling and grouping people will challenge community tradition in many locales.

- Sustaining the life of community groups and organizations through active participation in them, through preparing and supporting people for leadership roles, and encouraging and supporting a posture of welcome and support for newcomers will be activities that need increased attention.

- Assuming more active personal and collective responsibility as trustees or stewards of our own future implies a more public life for many people.

- Expanding the idea of tolerance so that conflict is resolved without oppressive tactics, anticipating diversity of opinion, and developing negotiation as the preferred way of resolving disputes in communities will challenge some communities' tendency to dismiss or even crush dissent.

- Promoting an appreciation about the idea of power-with others, which involves personally seeking out affiliations with individuals whose condition or experience makes them vulnerable, requires citizens' active participation. This is not a passive activity.

The challenge of an emerging inclusive social policy requires an identification of and with the people who have been excluded or kept separate.

Specific Implications for Communities/Citizens:

•Ordinary children will learn about children who have disabilities through day-to-day association.

•Every citizen will be more likely to have a neighbor who has a disability.

•If the focus is on the capacity rather than on deficits of an individual, there is more likelihood that people will be included in community life.

•Community members will increase their capacity to notice ways to "help" and "assist" those around them.

•People with disabilities will become better known and more present in neighborhood life. Their needs—and their gifts—will become more visible.

•Children will grow up in a different world than they grow up in now, and it will be a world where differences among people will be celebrated.

•People's family, friends, and fellow community members will increasingly play roles that are now played by paid professional service workers.

•It will be more-widely acknowledged that someone's personal security is highly dependent on his/her relationships with others.

•The "solution" of sending people, whose situations are difficult, to remote places will no longer be available. Communities will no longer exile members who have difficulties.

•More of the time of the average citizen will be spent in the company of people who have typically been excluded. This will lead to a "values shift" in what citizens think of as "good", "beautiful," "important".

•People will be presented with many more opportunities to create solutions and offer useful support to their fellow-citizens who have disabilities.

•Communities will be at risk of isolating people in different ways—i.e., there is a risk that "human services" could be replaced by pockets of poverty or violence, and/or ghetto-ized neighborhoods—unless sufficient cautionary steps are taken.

•Community members will help, speak for, and defend each other.

•Communities will remove disincentives to work, for citizens with developmental disabilities (e.g., insurance companies that refuse coverage, uncertainty about job security that leads to high reliance on benefit-programs). Businesses will consider changes (people

Assuming more active personal and collective responsibility as trustees or stewards of our own future implies a more public life for many people.

whom they had not previously considered as employees, supports at the work place, cost implications, etc.).

- Affirmative action, by communities, will help bring about good homes, good jobs, etc. for people with developmental disabilities.
- Community members will learn to see their neighbors who have disabilities as "people first".
- There will be more active participation by people with developmental disabilities in voluntary groups (e.g., churches), and these members will make valuable contributions to the groups.
- Some sort of "cushion" for risk-taking and learning will be necessary, so that error leads to learning instead of to hurt for people.
- People will be more involved in community political life—public decision-making.
- Friendships will be made; invitations to friendship and relationship will be issued.
- Community members will have to learn to shift their trust—away from human service systems, and to other people as major means for helping people who experience difficulties in life.

Promoting an appreciation about the idea of power-with others, which involves personally seeking out affiliations with individuals whose condition or experience makes them vulnerable, requires citizens' active participation.

Epilogue

The Community Living Paper states that positive change in the lives of people with and without developmental disabilities will most likely take place within the context of community and the structures established to back-up and support community living. With this belief in mind, the paper is meant to become a source of conversation and debate and a basis for planning for people with developmental disabilities and those who love and support them in Ohio's communities.

One of the issues that reviewers of drafts of the Paper debated frequently was a perceived absence of "answers" to problems posed by the Paper—a lack of a blueprint for the future of services in the state. During the course of the work on the Paper so far, the writers decided that a prescription was not what was called for. Instead, the task was to challenge people with developmental disabilities and those on whom they rely for support to try to find answers as close to their homes as possible—preferably inside the front door.

As a final-year activity of the Ohio Developmental Disabilities Planning Council grant that sponsored the writing of *The Community Living Paper,* a series of discussions and forums will take place in the autumn and winter (1992-93) in places where the project consultants are invited. These gatherings will occur in places as diverse as schools, living rooms, community centers, board rooms and state offices. The structure of these gatherings will vary from site to site, depending on those who have asked to take part in them. Some may be presentation-oriented, so that groups of people can hear the Paper's ideas explained, while others will be work sessions with people who wish to use the ideas in the Paper to plan for changes in their community. It is expected that there will be discussion of the implications of this Paper's vision for governmental agencies that are charged with seeing to it that the financial resources made available by the citizenry are used wisely to benefit people with developmental disabilities in Ohio's communities. Particular emphasis will be given to discussions that include both people who have developmental disabilities and others who are close to those people.

A brief chapter will be drafted that reviews the reactions and plans-for-action that surface during this series of gatherings and forums around Ohio. This chapter will be distributed as the real epilogue to *The Community Living Paper.*

Notes.

[1] Bellah, Robert., et al. *The Good Society.* p. 293.

[2] Cleveland may be the first city in the U.S. whose schools provided a class for children with mental retardation. Sarason and Doris (1979) mention a class established for one school year in 1875. It was judged a failure and terminated at the end of its first year of existence (in: Sarason, Seymour and Doris, John. *Educational Handicap, Public Policy, and Social History.* New York: The Free Press, 1979, p. 275.). The Cleveland schools tried again in 1936, establishing six "pilot" classes, with parents responsible for transportation of their children. This experiment lasted until 1940 when it was abandoned. See: Schmidt, Sally Nowak. *Out of the Shadows.* Cleveland: The Council for the Retarded Child, 1970.

[3] John McKnight, "Beyond Community Services." Center for Urban Affairs and Policy Research, Northwestern University, 1990.

[4] Phyl Sharratt. "What's Happening in Guelph?" *Entourage* (vol. 4, no.1, Winter, 1989), 18-20.

[5] Shafer, Michael S., et al. "A Survey of Nondisabled Employees' Attitudes Toward Suported Employees with Mental Retardation". Journal of The Association for Persons with Severe Handicaps (Vol. 14, No. 2), 137-146.

[6] We do not intend to imply that there is anything wrong with relationships between or among people who have developmental disabilities. We know lots of people who have built and who maintain strong ties with others whom they have met at (segregated) school, at workshops, in residential programs, etc. Indeed, some of these connections are vital ones, and their continuation is of greatest importance for the people involved. A major thrust of our argument, however, is that their experience (lived out in separate "programs") has not enabled people with developmental disabilities to form other kinds of relationships.

[7] John McKnight "Beyond Community Services", unpublished essay, 1990.

[8] Cynthie Johnston, Ohio Department of Mental Retardation and Dev. Disabilities. Personal Communication.

[9] Formerly called state institutes or state schools.

[10] It is difficult to be accurate about these numbers, especially because Ohio's definition of "developmental disability" has undergone change recently and statistical surveys of this population outside of persons enrolled in County Board of MR/DD programs may be unreliable. The best measure, which is far from perfect, is that ODMR/DD reports that 22,000-25,000 (sources differ) adults are enrolled in Ohio's 88 County Board of Mental Retardation/Developmental Disability programs. When the number of people living in Ohio's various residential "facility" options for adults (ICF-MR's, Nursing Homes, Purchase of Service Homes) is deducted from the number of people in County Board programs, just about half of the eligible people live in non-paid situations—including the homes of their families.

[11] ODMR/DD, Office of Adult Services, "County Board Individual Information Form, Adult Program Data", January, 1992.

[12] John O'Brien and Connie Lyle. "More Than Just a New Address: Images of Organization for Supported Living Agencies." Lithonia, Georgia, 1991, pp. 24-25. Adapted from: Starhawk (1987). *Truth or Dare: Encounters with power, authority, and mystery.* San Francisco: Harper & Row.

[13] Wendell Berry. "The Work of Local Culture." in *What Are People For?* San Francisco: North Point Press, 1990, p. 157.

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