

Book Chapter

The Place of "Choice"

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Introduction

Dorothea Lynde Dix, in her 1843 address to the Massachusetts Legislature exposing the plight of people who were poor, disabled and in government care, declared: "Familiarity with suffering, it is said, blunts the sensibilities, and where neglect once finds a footing other injuries are multiplied"¹

In considering the organization and implementation of services for people with retardation, I would like to suggest that we take care not to elevate "choice" above other values. An unbalanced emphasis upon choice risks, recalling Dix's words, multiplication of the neglect to which people with retardation have been subjected for too long.

The current desire to see "choice" as a dominant theme in both individual planning and system design is likely to be temporary, and to be superseded by other themes as we move to another stage in the realization of normalization, that of integration.²

Just as the theme "quality control" was superseded by "quality assurance" and "quality enhancement,"³ so "choice" will later be seen in context as a small, albeit important, pan of ensuring quality, responsive services to people who are in our communities.

Some writers, perhaps enamored of the philosophical connections between "choice" and "freedom" or perhaps connecting liberation from institutions with some notion of freedom, seem to extol "choice" as a value supreme to others. For example:

Choice, personal freedom, and personal empowerment are the rubrics that, perhaps more than any other, signal the presence of the new way of thinking or the new paradigm in the design of supports to people with disabilities.⁴

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The purpose of this essay is to reflect on the limitations of choice as a guide for decision-making at the individual, service provider and systems levels. I do not intend to discuss the subject in all its ramifications, but merely to provide an initial basis for critical examination.

Energizing this examination is a current tendency in practice which justifies what I would label deprivation or denial of services, or violation of rights, of people with retardation based on invocation of "choice" as a guiding

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principle. For example, people are denied individual habilitation planning, or even a case manager, (in a system where a plan and case management is prerequisite to any assistance at all) because they are said to have chosen to give up such assistance. People are denied a job or meaningful activity during the

day or evening because they are said to choose otherwise. People's homes and bedrooms, and daily life choices, are barren and devaluing, all based on what is said to be "choice."

As in Herman Melville's story, "Bartleby the Scrivener," unqualified deference to the preference "not to" leads to isolation, devaluation and harm.

I consider "choice" from several perspectives:

- the relationship of choice to the real world options available to people with retardation:
 - the relationship between choice and other values;
 - the relationship between choice and the law; and,
 - the relationship between choice and the chooser.

My purpose is not to describe all the limitations of choice in retardation services, but rather to assist people with retardation, and their advocates, friends, supporters and service providers, with perceiving and beginning to understand those limitations.

"Choice" and Real World Options

The notion that primacy should be given to the articulated choices of people with retardation or their surrogates presupposes that they are at liberty to exercise choices among many options. Otherwise, they are like the magician's volunteer, compelled always to choose the "force card" from the card deck, while imagining that any one of the fifty-two cards was a possible outcome.

At least four categories of obstacles limit the available options: a) the persistence of institutions, b) the persistence of abuse and mistreatment, c) the effect of class, stigma and the nature of bureaucracies, and d) the inadequacy of many community programs.

A. PERSISTENCE OF INSTITUTIONS

In his detailed prescription of the meaning of the normalization principle in the United States, Gunnar Dybwad twenty-five years ago asked the question, "The Old Institution: Renovate or Discard?" He answered that fixing the institution "is at best ill advised, and at worst unfeasible, and a poor service to the residents now housed in such institutions."⁵ Many have come to that conclusion since that time.

Viewed from one perspective, there has been tremendous progress in implementation of this "discarding" of institutions. Between 1950 and 1970, more public retardation facilities were added than in any other period in United States history, and the number of people with retardation in public institutions grew from 116,828 in 1946 to its peak of 193,188 in 1967, a 65 % increase which was nearly twice the rate of increase in the general population; by 1988, the number had decreased to 91,440.⁶ Since 1970, 44 institutions for people with retardation have closed or are scheduled to close.⁷ In New York, the institutional population dropped from a high of 20,000 to about 7,000 a few years ago.⁸

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If the question asked is, where have people gone to, the answer may be jolting for some of us. Among people remaining in large institutions, there are more in private institutions than in public institutions.

From June 30, 1982 to June 30, 1991, the number of people in large private ICF/MRs increased by 9,311, while there were 31,830 fewer people living in large state-operated ICF/MRs (Table 1).⁹

Large private institutions have replaced the large public institutions. Although many people with retardation are now enjoying the fruits of life in the community, many more remain in large congregate institutions. Three-quarters of the funding from the federal ICF/MR program, the principal fiscal support for deinstitutionalization, in fiscal year 1985 provided for institutional, not community, placements.¹⁰

**Residential Facilities for People
With Mental Retardation
United States, 1988**

<i>Type of Facility</i>	<i>Number of Clients</i>
Public Institutions	91,440
Congregate (16 or more beds)	
Large Private Facilities	46,351
Private Nursing Homes	50,606
TOTAL	96,957
Small (less than 16 beds)	
Public ICF/MRs	3,355
Private ICF/MRs	23,949
Other Residences	125,557
TOTAL	152,861

Table 1

We continue to use institutions for a majority of people with retardation receiving residential services. Institutions remain available for new admissions. The persistence of institutions, and their continued consumption of massive fiscal resources, are major inhibitors of the major reallocation which would be needed to enable free choices to be made.

B. PERSISTENCE OF ABUSE AND MISTREATMENT

For many decades, we have recognized the abuse and mistreatment to which we subject people with disabilities. We have long been familiar with the abuse and neglect so prevalent in institutions.^{1M3}

Both in institutions and in community programs, abuse and neglect continue to harm people with retardation.¹⁴⁻¹⁶

Beyond the spectacular abuse, there is a day-to-day form of mistreatment which has changed little for many people from Burton Blatt's characterization years ago. "The ordinary condition is boredom more than brutality, legal abuse more than illegal assault, and a subtle degradation rather than a blatant holocaust."¹⁷

Everyday lives, blessed with large and small choices, cannot be obtained by people with retardation without surmounting many obstacles, many of which have little to do with the retardation system itself.

C. COMMUNITY "OPTIONS," ECONOMICS, MINORITIES, STIGMA AND BUREAUCRACIES

Everyday lives, blessed with large and small choices, cannot be obtained by people with retardation without surmounting many obstacles, many of which have little to do with the retardation system itself.

People with retardation and other disabilities are more likely to be poor, unemployed, underemployed, and to be denied economic benefits and status which are accorded to people without disabilities. Women with disabilities fare worse than men with disabilities: members of ethnic and racial minorities encounter greater barriers than nonminorities.¹⁸ While there may be little which can be done in the short run to rectify the resulting inequitable distribution of services and wealth, and the stigma which attaches to disability, it is important to keep sight of these issues when one examines choices which are made by or for people with disabilities.

The negative valuation of the social status of people with retardation results in individuals being confronted at virtually every turn with restrictions on choice.

The negative valuation of the social status of people with retardation results in individuals being confronted at virtually every turn with restrictions on choice. Applying for a job or housing, ordering food in a restaurant or seeking friends, for example, are all occasions on which stigma

and stereotypes may make it impossible for a person to "choose" options which nondisabled people take for granted.

There is a menu of service styles available today including a variety of individual supports, independent and semi-independent living, foster care, group homes, and the like. This variety creates an illusion of choice. There is no doubt that people with retardation who have moved to the community from institutions are in most cases flourishing. ^{There is a "insidious danger of assuming that the development of placement Qm ^ ^ matching clients with the facility most appropriate" for the person.}¹⁹

In addition, bureaucratic program restrictions inhibit effective exercise of choice. John O'Brien and Connie Lyle O'Brien have pointed out that consumer choice is severely inhibited, if not altogether precluded, by government agency control of service structures:

However, most people with developmental disabilities who live outside their family's homes or residential facilities now depend on a supported living agency because current public policy severely restricts people's option to control their share of available funds. And even when people with disabilities gain full control of available cash—as the authors believe they should—it is reasonable to assume that some people will probably choose the convenience of purchasing services from a supported living agency over the investment of time required to self-manage a personal support system.¹⁰

Contradictory service system assumptions result in continued devaluation of people served in the community. Foreexample, some people who live in and control their own homes nevertheless "spend their days in mindless, segregated activities."²¹

D. COMMUNITY "OPTIONS": OUT OF THE FRYING PAN

There is no doubt that people with retardation who have moved to the community from institutions are in most cases flourishing. They are working, have homes and friends, and are participating in their communities. They are learning from others and, perhaps of greater importance, are enriching their neighborhoods and towns.

For many, however, there has been, in Burton Blatt's prophetic phrase, a "reformation to sameness."²² We have established many baby institutions which, although relatively small and located in the community, may grow up to be larger and more oppressive. Some residences have routines and an ambiance in which boredom, routinization, and compliance are the primary

elements. Some community "services" are so abusive and neglectful as to recall the institutions for observers as well as clients.

An example of the "out of the frying pan, into the fire" aspect of community services is the status of former residents of the Pennhurst institution, a facility closed in 1987 under a court order. During the day, even in a community in which the individuals are protected by the landmark court order, most

people spend most of their time in segregated "day activity" and sheltered workshop programs. Class members in the Pennhurst case in Philadelphia, by provider agency, spend 81% to 100% of day service hours in segregated settings. Only 1.4% are in what is nominally called "community integrated employment" and, of those, the majority are not paid and not actually working.²³

Excessive respect for the abstract notion of "choice" can lead to the perpetuation of neglect or to an increase in the risk of neglect and other harms.

The court found in 1994 that the abuse/neglect investigation system is inadequate, the medical care provided is insufficient, and that individuals in the community are not being provided the individual planning and other services to which they are entitled.^{24,25}

Thus, although in terms of many aspects of personal growth, individuals do relatively well in the community, they sometimes do so despite the failure of the government or provider agency to ensure that needed conditions and safeguards are in place. In such situations, true exercise of "choice" is adventitious.

E. RESPECTING CHOICE AND PERPETUATION OF NEGLECT

Excessive respect for the abstract notion of "choice" can lead to the perpetuation of neglect or to an increase in the risk of neglect and other harms. As I discuss in the next section, choice must be kept in context, and other values (sometimes competing and sometimes complementary) must be weighed in the balance.

In 1864, Dr. Edouard Seguin emphasized that affirmative encouragement is a responsibility of the teacher of people with retardation. Seguin's religiously motivated interest in people with retardation encouraged his development of sensory, muscular and speech training as the methods for what is today called habilitation. If we can set aside for the moment his negative characterizations and language which would not be acceptable today, his words are an interesting reminder from more than a century ago that respect for "choice"

cannot ignore the need for a proactive relationship with people with disabilities:

The incessant volition of the moral physician urges incessantly the idiot out of his idiocy into the sphere of activity, of thinking, of labor, of duty and of affectionate feelings; such is the moral treatment. The negative will of the idiot being overcome, scope and encouragement being given to his first indications of active volition, the immoral tendencies of this new power being repressed, his mixing with the busy and living world is to be urged on at every opportunity. This moral part of the training is not something separate, but is the necessary attendant and super-addition upon all the other parts of the training, whether we teach him to read, whether we play with him the childish game, let our will govern his, if we will enough for himself, he shall be become willing too.²⁴

Unchanneled deference to choice can be a excuse for neglect. It is easier to go along with choices which mean less work, less expense, less relationship, or less caring than it is to truly assist someone in identifying the larger universe of options, exploring those options, and coming to grips with the struggle to realize a choice truly made or the disappointment of the impossibility of realizing the choice.

"Choice" and Other Values

A. CHOICE IN CONTEXT

How we value and articulate choice has changed, even during the "modern" era of services for people with retardation. Before government funding for community services, for example, "choice" meant simply providing parents with a choice of community services; the emphasis

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was on the locus of community or institution.²⁷ Today, with community life more differentiated, choice often means "things as selection of types of services (independent living, apartments, group homes, etc.),

particular opportunities for employment or other day activity, and uses of leisure time.

Although "choice" (or its sister concept, "empowerment") is described by some as a transcending or unifying value, replacing others such as normalization or rights or habilitation, those

who articulate what is now being called a "new paradigm" do not give such pre-eminence to "choice." Instead, they recognize that the present

emphasis on participation of people with retardation as full citizens, and in relationships with others, is inherent in the normalization first articulated twenty-five years ago.⁸

Valerie Bradley describes a three-stage process: the institutionalization era ending in the mid-1970s, the community development era beginning at that time, and the "third and emerging stage is the era of community membership, which is marked by an emphasis on functional supports to enhance inclusion and quality of life as defined by physical as well as social integration."²⁹

"No single categorical principle has ever had a greater impact on services for mentally retarded persons than that of normalization."³⁰ Codified in a Danish statute in 1959, the concept was explained in 1969 by Niels Bank-Mikkelsen. Director of the Danish Service for the Mentally Retarded, as embodying "a basic right to receive the most adequate treatment, training, and rehabilitation available and to be approached in an ethical fashion."^{31,32}

Bengt Nirje, then director of the Swedish Parents Association for Mentally Retarded Children, defined normalization as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."³³ We have generally accepted the normalization as the "one unifying principle" which, as it evolves, "expresses the aims, attitudes and norms implied in quality work for and with the mentally retarded."³⁴ The principle applies to all people with retardation, regardless of level of disability or residential setting, and is "useful in every society, with all age groups, and adaptable to social changes and individual development."³⁵ Therefore, "it should serve as a guide for medical, educational, psychological, social and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong."³⁶

Normalization does not exclude respectful response to the choices of individuals. Its early formulation explicitly recognized this: "The normalization principle also means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as nearly as possible, and respected."³⁷

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There are values embodied in normalization other than choice. Nirje's formulation of twenty-five years ago includes:

- normal rhythm of the day;
- normal rhythm of life, including participation in the regular society;
- normal rhythm of the year;
- opportunity to undergo normal developmental experiences of the life cycle, with maximum contact with normal rather than a deviant society;
- respect for choices, wishes and desires of the individual;
- life in a world including men and women;
- enjoyment of normal economic standards and work opportunities;
- and,
- standards for physical facilities the same as those for ordinary citizens.

In addition to "choice" as an explicit central element of the normalization principle, the other elements imply acceptance and encouragement of indi-

vidual choice. For example, integration with the society as a whole increases knowledge of options and the consequent opportunity to choose among homes, friends and activities. Decent living conditions and economic power expand one's choices as well.

One response to the normalization principle has been to seek structures for acting responsively and responsibly, with the person (rather than the professional team, or the family, or the government) at the center of attention.

Wolf Wolfensberger's re-definition of normalization emphasized social integration and directed attention to the obstacles preventing it. Normalization is:

Utilization of means which are as culturally normative as possible, in order to establish, enable, or support behaviors, appearances, and interpretations which are as culturally normative as possible.³⁸

Interaction with the community is key. "Ultimately, integration is only meaningful if it is social integration; i.e., if it involves social interaction and acceptance, and not merely physical presence."³⁹ The 1983 reformulation of normalization as "social role valorization" continued to pay close attention to the roots of devaluation of people in our society, and mechanisms to end that devaluation.⁴⁰

B. CHOICE AND PERSON-CENTERED PLANNING

One response to the normalization principle has been to seek structures for acting responsively and responsibly, with the person (rather than the professional team, or the family, or the government) at the center of attention.

Such person-centered planning of necessity has called upon us to focus on choice, both because those assisting in the planning need to listen to the choices made by the individual and, in many cases, to aid in the choice-making.

Choice has high visibility in person-centered planning:

Many people with disabilities have been denied the life experience and opportunity needed to make informed choices.

We have suppressed expressions of choice by consistently failing to honor the expressions of choice that are made, Where people have not been trained into passivity, they have been forced into rebellion and their expressions of choice have been distorted in the process.

None of those leaders who have developed person-centered planning have elevated choice above the other values inherent in normalization.

The effects of the disability have been used as an excuse to make choices for people. * * * With these individuals, efforts must focus on understanding the individual. Person-centered planning efforts simply provide a structured process by which this understanding can be achieved.⁴¹

None of those leaders who have developed person-centered planning have elevated choice above the other values inherent in normalization; all, in fact, take as the fundamental base all the elements of normalization and all recognize how easy it is for the person to be dropped from the center of the planning. For example. Beth Mount warns:

When the system takes over the futures planning process, the activity immediately loses its power, flexibility and responsiveness, quickly becoming one more intrusive, insensitive and ineffective activity. When people lacking strong person-centered values are given the power to conduct a procedure that has no potential to change the system of which it is a part, then futures planning becomes one more way to process people through a series of empty and meaningless rituals.⁴²

C. RESPECTING CHOICE AND NEGATING VALUED LIVES

Some people might suggest that normalization did not pay sufficient attention to choice and that therefore normalization should be superseded by a new unifying principle: "choice." It is said by some that, since a person with retardation might choose, for example, to not work or to live in a large segregated group home, or to dress abnormally, or to spend time in segregated activities, one must accept this "choice" as part of normalization or accept it as a limitation on normalization.⁴³

Acquiescence in such "choices" is a destructive elevation of choice among other values which constitute the normalization or social role valorization principle. As Wolfensberger has pointed out:

Thus, for the largest number of devalued persons, the *right not to be different* in certain dimensions of living is actually a much more urgent issue than the right to be different. When we recall that the overwhelming response of society to devalued people is segregation, expressed partially by its confinement of vast numbers of citizens to institutions and partially by sequestering devalued people in other nonnormative settings, we realize that the right not to be segregated and institutionalized (which is almost equivalent to being made different, or more different) is really a bigger issue than the restrictions of individual choice, which, left to itself, would more often than not result in a choice of something that would fall within the range of the cultural norm anyway.⁴⁴

Some people with retardation may deliberately choose nonnormative ways of life, or of dress, or the like. The exercise of such choice is itself culturally normative. Friends and supporters of the person would respond in the same ways in which we re-

Choice is not enough. Seymour Sarason warned that the choice of persuasion, pedagogy, option ignored the social context modeling and other forms of culturally normative social influence and could rob the larger community of the benefits of integration. to steer a person toward a course of action one desires. Second, one imposes coercion only where one would do so legally in the larger societal context, i.e., where one would do so with other (valued) citizens of the same age. Third, one chooses the least restrictive alternative, if one does coerce."¹

Choice is not enough. Seymour Sarason in 1969 noted the limitations of simply allowing parents to have "freedom of choice" to place children with retardation wherever they wished. Although he recognized this would allow use of some small residential facilities as an alternative to needless institutionalization, he warned that the choice option ignored the social context and could rob the larger community of the benefits of integration:

When we consider the value of choice, we must do so in the context of the other values which inform our society in general, and services for people with retardation in particular.

As a reaction to our present way of handling residential care, the proposal has merit. However, I must express the serious reservation that the proposal perpetuates the tendency to think primarily in terms of the retarded child and not in terms of the possible relationships between the field of mental retardation and other community needs and problems. To the extent that a plan for residential care does not reflect the systematic exploration of the alternative ways in which it can be related to other community needs and problems—that is to say, truly integrated with the activities of diverse groups and settings in the community—to that extent the field of mental retardation and the larger social community will be robbed of the benefits they can derive from one another.⁴⁶

When we consider the value of choice, we must do so in the context of the other values which inform our society in general, and services for people with retardation in particular. Otherwise, we are perverting the principle of normalization either through misunderstanding or through failing to articulate compromises which result from inadequate resources or will.⁴⁷

"Choice" and the Law

A. PERSONAL RIGHTS

Rights have many sources in our culture, ranging from enforceable enactments of legislatures to organizational expressions of desiderata. For people with retardation, there have been many declarations of rights by the United Nations, American Association on Mental Deficiency, and other groups.^{48,50} Courts have set standards for treatment.^{51,58} Legislatures have articulated standards as well.^{59,1}

Common to those expressions are rights to education; training; habilitation; medical treatment; humane care; protection from harm, abuse and exploitation; and the right to

the least restrictive individu-

Profoundly relevant to the degree of ally appropriate environment. freedom which a person with disabili- Included in some rights
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abilities may express and implement—are rights to eco-

nomic security, a decent standard of living and employment. For example, the United Nations 1971 Declaration of General and Special Rights of the Mentally Retarded provides, "The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation."⁶³ The 1993 United Nations Standard Rules on the Equalization of Opportunities for Persons With Disabilities provides for "equal opportunities for productive and gainful employment in the labour market." For caretakers of people with disabilities, the Standard Rules provide for "income support and social security protection."⁶³ The 1973 AAMD rights include the "right to gainful employment, and to a fair day's pay for a fair day's labor."⁶⁴

For those rights which are enforceable, there is an affirmative duty on the government in the United States to either provide services or to ensure that there is no violation of those rights. For example, retardation institutions must provide treatment and protection from harm to those who live there.⁶³ Rights in the community post-institutionalization are also protected; a state may not end its duty to people it has incarcerated simply by discharging them to community programs.⁶⁶⁻⁷¹

B. CHOICE AND WAIVER OF RIGHTS

A person with retardation may not give up an important right—for example, a right to an individual treatment plan or a right to habilitation or a right to community services—casually. The "choice" to surrender such a right may not be freely or easily made.

A person with retardation may not give up an important right casually. The "choice" to surrender such a right may not be freely or easily made.

The legal obstacle to the exercise of this rights-waiving choice arises from the requirement that a choice which rejects such an important right is permitted only after the occurrence of procedures designed to examine that choice. Understandably, a decision to accept a benefit is assumed to have been freely made; however, a decision to reject important benefits is seen as subject to such alikelihood of misunderstanding or possible undue influence that it is not permitted absent safeguards.

The rights discussed above are personal rights and are possessed by the individual. In one illustrative and influential case, for example, state

Texas, and local governments sought to demonstrate compliance with a court order by showing that community services were adequate for the vast majority of the plaintiff class. The

federal court of appeals, agreeing with the trial court, found that, because the right to adequate habilitation extends to each person individually, the government defendants were in contempt unless each and every class member's rights were implemented. Compliance is measured person-by-person.⁷³

Fundamental legal principles require that waiver of a right be knowing and with awareness of both the nature of the right and the consequences of waiver. For example, when a person is subject to proceedings to commit him or her involuntarily to a mental institution, the right to have a hearing and to be present may be waived only with the approval of the court.⁷⁴ In many jurisdictions, a person with retardation may not be sterilized without a hearing and a judicial determination approving the surgery.⁷⁵

While, generally, there is no affirmative right to receive services when one is not in an institution,⁷⁶ there is a growing body of law which provides some protection of a right to community services in some circumstances. Some courts ground the right on the general right to treatment for people in or leaving institutions; others find a source in state law, and still others adopt and enforce settlement agreements between the parties.⁷⁷ One recent settlement requires California to reduce the population of four institutions by 2,000 residents over five years.⁸¹ Regardless of the source of the right, it is no small matter for the individual to give it up. Even the existence of an arguable right gives a person leverage in negotiating for governmental aid.

If a person is purportedly choosing to give up a right or benefit which is important, such as a community home or the right to an individual habilitation

Fundamental legal principles require that waiver of a right be knowing and with awareness of both the nature of the right and the consequences of waiver.

"Choice" and the Chooser

A choice may be attributed to the person with retardation which is not the choice of that person. There often is another "chooser" who, in the background or quite directly, actually makes or directs the choice.

While we may sometimes accept surrogate or *sub silentio* choice-making, such acceptance should be conscious and should acknowledge that, from the perspective of the person subjected to the choice, it is imposed. The greater the social and personal distance between the chooser and the chosen-for, the greater is the likelihood of the choice being false or mistaken.

A. PARENTS' CHOICE

Parents of people in institutions often choose continued institutional care and vigorously reject community placement. A 1985 study found that 58.2% of parents would not approve ~~of placement under any circumstances-~~ The phenomenon is nothing new. "A corollary of our present ideological confusion is the strong but inappropriate ideology prevalent today that parents have a right to decide whether to keep a retarded child or whether to divest themselves of it. The literature is replete with this implication, or with explicit statements that, 'the placement decision is the parents.'"⁹⁰

^ *greater the social and personal distance between the chooser and the chosen-for, the greater is the likelihood of the choice being false or mistaken.*

One cannot accede to parental opposition because, first, it may not be in the interests of the person in the institution, and, second, there are serious limitations on the parental view which arise from misunderstanding of community services, anxiety about the unknown, and other factors. Many parents who initially disagree with placement change their minds and become supporters after placement occurs. At the least the parents' decision-making is quite complex.^{91,93}

One court deferred to parental decision-making with regard to minors for whom professionals have chosen community placement where evidence on a preferable setting is found to be conflicting, and where the pro-community decision was that the new home would be "more beneficial."⁹⁴ In that case, the trial court had ordered placement but the appeals court found that the parent's views, while not sufficient to automatically veto placement had not been afforded sufficient consideration.

plan and its implementation, then the waiver should be reviewed through a fair hearing process in which the person has an advocate who presents the point of view which favors retention of the benefit.

C. EXCLUSION OF OPTIONS

One does not have the ability under the law to choose anything one wishes. Some options are excluded or forbidden, either in the interest of the community's overall welfare or as a result of governmental authority to set priorities and allocate its resources.

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Generally, we permit a person to choose among alternative services. "If several alternative service options exist for a given client, and if all these alternatives can be considered rightful, it is widely accepted that the client has the right to choose which option or even combination of options should be implemented."⁸² However, the "rightfulness" of the options is subject to change.

The federal and state governments have the authority to exclude certain treatment options for people with retardation. This may result from funding decisions (for example, extending financial aid or health benefits to certain types of care) or from a fiat simply shutting down an institution or a program.^{83, *7}

There are other "options" for life choices which are flatly forbidden, even absent any government involvement. For example, peonage (forced and uncompensated labor) is forbidden, as is sexual abuse, and subjection of people with retardation to secret or unconsented dangerous experimentation.

There are likely to be choices which, for one reason or another, the law denies to a person with retardation even in the face of a demand from the person or a representative. In some states, the choice of an institution may not be available. In others, a particular program model may be denied.

The degree of scrutiny with which the law views a distinction targeting people with retardation will vary depending on the consequences to the person of denial. Martha Minow explains:

[T]he premise is that relationships between people are what matter, and attributions of difference that build obstacles to such relationships are suspect. Isolation itself may contribute to false views of difference that impede or obstruct relationships, and isolation of a powerless minority group by a powerful majority should raise special suspicions for a court that focuses on relationships and power."

B. GOVERNMENT'S CHOICE

The absence of a mandate for community services for all in the United States results in state and local government making choices about who to

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serve. Such governmental choices restrict what is available, leaving the person with retardation to make a forced "choice," not a free choice. It is important that we not mistake one type of choice for another.

A 2002 federal court decision examined in detail how Rhode Island, then in the process of closing its one institu-

tion, handled in its Medicaid Plan what the court called its "shortage of space in private and small public ICF-MRs." The court found that one's chance of receiving an ICF-MR bed depended on "good timing and luck" as a "natural characteristic of any shortage of goods under price regulation." Because the state offers all eligible people the choice of the institution, there was no violation of Medicaid law.⁹⁵

In Kansas, counties contract with private providers for community services. A county embroiled in a dispute with one provider called Terramara terminated its contract with the agency which had provided a work activity center, housing and other services. Terramara's clients were given just over 45 days to either switch to the new contracted provider which the county had just formed, Flinthills, Inc., or to lose any preference for being served by Flinthills. A court upheld the county's ability to force this "choice" on the clients of Terramara who, in the county's view, could choose to continue at Terramara but only at the person's own cost.

A federal court in a lawsuit challenging the provider-switch in Kansas recognized that the plaintiffs (individuals with retardation) "have fundamental constitutional rights to live where and with whom they choose, to pursue employment through workshops, to associate with their friends, to live in group housing arrangements as provided by Terramara, and to make fundamental choices affecting their lives."⁹⁶

In our system, the government cannot be relied on as a provider or source of funds for services. About 181,835 people in the United States are on "waiting lists" for retardation services.⁹⁷ In terms of the numbers of people

affected, federal, state and local governments, which determine eligibility and make allocations, are the primary choosers of who gets what.

C. PROVIDERS' CHOICE

In terms of the numbers of people
 Service providers often have a limited number of options for the *affected, federal, state and local* people they serve; the public agencies which fund such providers often *governments, which determine eligibility and make allocations,* require a person to be served by a *are the primary choosers of who* particular agency based on geography *gets what.* or the happenstance of a contract award.

Thus, if the provider has group homes and apartments, for example, the person's choice is between those two options. If the provider has a day habilitation program, a sheltered workshop, and a mobile janitorial service, the person's choice would be limited to those possibilities.

Despite the virtually overwhelming control which rests with the provider, the person's unchosen residence or program may nevertheless be denominated the person's "choice." A recent federal court decision illustrates the situation. Allied Health Care, Inc., operator of two community homes in Louisiana, claimed that zoning restrictions violated the Fair Housing Act. The homes, which had been duplexes, were renovated into single family homes, and then Allied had opened an "internal passageway" between the two homes. Local zoning law restricted each of the two homes to four unrelated persons each, for a total of eight. Allied intended to operate with six persons in each home, for a total of twelve.⁹⁸

Although Allied professed adherence to normalization, its explanation for the need for a twelve bed site was based on Allied's claim (supported by the court) that it could not operate with fewer residents because "payments received from Medicaid and SSI" would not offset the expenses. The court determined that there was no violation of the Fair Housing Act's prohibition on discrimination against people with disabilities because the zoning ordinance "has the practical effect of limiting the ability of the mentally handicapped to reside in the residence of their choice in the community." However, the court cites no evidence that any person actually made a choice to live in the twelve-bed site and no person with a disability was a party to the lawsuit.

A contrary court decision, one which correctly recognizes that a provider cannot exercise a choice for residents which limits integration, rejected a challenge to a zoning ordinance which precluded placement of residential

facilities within 1,320 feet of existing facilities." Familystyle had thirteen homes on one street, four homes on another street, and other homes as well. It sought to occupy one home with 13 residents, another with six and another with four. Specifically finding that the zoning rule does "not prohibit mentally ill persons from renting or buying a home within 1,320 feet" of another home (thus respecting an individual's personal choice), the court upheld the restrictions as applied to a "facility provider":

The state has determined that a proper setting is one which is, as much as possible, in the mainstream of the community. Forcing new residential facilities to locate at a distance from other facilities by its very terms prevents the clustering of homes which could lead the mentally ill to cloister themselves and not interact with the community mainstream. Because the state and local laws prohibit this clustering effect, they do further the goal of integrating the handicapped into the community.

D. PROFESSIONALS' CHOICE

Related to the influence of providers on general program-type choices is the often determinative choosing which is performed by professionals.

Just as persons with disabilities may have limited opportunities to exercise personal choice and autonomy on a daily basis, it is also quite unusual for them to be actively involved in the development of their service plans (e.g., educational, habilitation) programs. * * * Far too often, educational, residential, and vocational placements reflect the choice of well-meaning parents and staff rather than the preferences of the individual with the disability.¹⁰⁰

During the 1980s there was a significant professionalization of retardation services, with interdisciplinary teams and other bodies assigned to make choices for people.^{101,102} Professionals continue to wield considerable authority and to make choices for people in their charge, and the law often upholds that authority.^{103,104}

E. NEIGHBORHOODS' CHOICE

Communities to which people with retardation are returning sometimes oppose development of community homes. Estimates of opposition to about 25 to 35% of residences underestimate the extent of opposition because they do not include those homes which fail to open or close early.¹⁰⁵ While, over time, opposition decreases and support increases, regardless of the

neighborhood's initial opposition,¹⁰⁶ the potential for opposition surely affects siting choices by governments and private providers.

F. RESPECTING CHOICE AND CHOOSING THE CHOOSER

Clearly, the preferred chooser is the person with retardation. Unfortunately, however, he or she is most typically the subject or victim of other people's choices. For those individuals who presently cannot express choices themselves, we must turn to various surrogate alternatives for both decision-rules and for specific decisions.

It is not sufficient simply to accede to parental desires for children or to turn over decisions wholesale to guardians of adults, or to professionals, providers or others. Whatever decision-maker is permitted to speak for the individual to make a specific decision, it is essential that the decision-maker be bound by decision-rules, and decision-processes, which reflect the imperative that "choice" be exercised in accordance with the principles of normalization and social role valorization and, thus, in favor of options which reflect physical and social integration, and culturally normative results.

Where the person's wishes are not known directly, efforts can usually be made to ascertain those wishes indirectly, both from the person and those who know the person well.^{107,108}

Where decisions are made which are so important that they have irreversible results, or will deny habilitation or other treatment, or will affect such basic interests as a person's liberty, the waiver of a person's rights should not be entrusted to a surrogate decision-maker alone but should be reviewed by a court, with the individual represented at the hearing by an advocate assigned to argue *against* the waiver of rights.¹⁰⁹

Regardless of our individual roles in the lives of people with retardation, it is essential to turn toward those people who are identified variously as consumers, clients, or who are

advocate for themselves. From the first "gatherings" of such groups in the 1970s, the demands of such organizations have been for the same things required by the normalization principle and the rights enunciated by the United Nations and by the courts:

community services rather than institutions, paid employment, maximum self-sufficiency, ability to choose helpers and services, involvement in Policymaking.¹¹⁰

Where the person's wishes are not known directly, efforts can usually be made to ascertain those wishes indirectly, both from the person and those who know the person well

Conclusion

Elevation of "choice" above other elements of normalization inevitably shortchanges the people who we serve. Their choices are often restricted by the deprivations to which we have subjected them or by denial of real-life experience with the options which we present to them.

People are also presented with fake or insincere opportunities to choose. Where a government agency or contracted provider has a short predetermined menu of alternatives, meaningful choice is not possible. For a person who

For a person who wants a job, a choice of which sheltered workshop station to sit at is not a real choice. For a person who wants her own home, a choice between group homes, or a choice of bedspread, is not a real choice. In

those situations, we have a tendency to retrospectively endorse such a fake choice as a real one, forgetting the narrowing of options over which the individual had no control.

If the goal is to enable and assist people to have access to a valued life and a valued culture, then we need to ask ourselves questions on each occasion where we believe we are providing, presenting or witnessing a "choice." Kristjana Kristiansen and others have begun to articulate these issues.¹¹¹ I would contribute these questions:

- What frame of reference is being used?
- How do we assist people in obtaining access to a better frame of reference when making choices?
- What is life like for other people of the same age, interests and goals? How do the prospective choices enable that life?
- Is the suggested choice likely to invite, risk or perpetuate neglect or other harm?
- Who is the most vulnerable in the situation? Who is at risk if particular choices are made? Who will be left out?
- Who is the chooser? Why is this the chooser in this situation? What voice does the subject of the choice have? Why not does he or she not have a greater or determinative choice?

With these questions both in mind and in practice, perhaps we can begin to see the place of choice.

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