
Autonomy and Competency — Self-determination in the Lives of Adults with Developmental Disabilities

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The principle of autonomy anchors decision making for most North Americans. For people with disabilities, however, the quest for self-determination is often countered by society's responsibility to take care of those who have some area of weakness or incompetence. Those who serve this population must, therefore, intentionally shift the balance of power to encourage independent living and to give people with disabilities a voice in their own lives. Changes in the system of care, training, and the way questions of competency are adjudicated are contemplated.

Americans have a long-standing regard for autonomy as an essential human right. As John Stuart Mill wrote, in the 1800s, citizens should be able to develop according to their own personal convictions, as long as they do not interfere with a like expression of others' freedoms.

Autonomy refers to what makes a life one's own. It is shaped by personal preferences and choices. Autonomy is not a universal concept, with one meaning in ordinary English and a similar consensus in contemporary philosophy (Beauchamp and Childress 1994). It variously means self-governance, liberty, rights, privacy, individual choice, and freedom of will. The applicable meaning for the purposes of this paper is "personal rule of the self that is free from controlling interference by others and from personal limitations that prevent meaningful choice" (Beauchamp and Childress 1994).

Self-determination requires two conditions. The first is liberty, or independence from controlling influences. The second is the capacity for intentional action (Beuchamp and Childress 1994). The patient's right to be informed about his or her health care treatment and the right to participate in decisions about his or her care are the bedrock of bioethics, at least in North America. However, the balance of interpersonal power shifts when one

party becomes the object of another's beneficence. The least powerful person in the relationship is generally the one with the greater need (Parenti 1978). The person who is ill leans heavily on the one who has healing power; hence, the frequent insistence on the principle of autonomy to ensure that the physician-patient relationship is neither paternalistic nor despotic. But in the case of people with disabilities, even professionals seem to be less certain.

Society has a history of being perplexed about how to respond to people with disabilities. People with disabilities have been feared, revered, and excluded from society, in turn. Beyond a vague expectation that people with developmental disabilities will be looked after by assigned professional staff, most Americans know little about the living conditions they face. People with disabilities are tolerated; they live on the fringe of society, separated from others by stigmatizing labels and their supposed inabilities. The purpose of this article is to examine the ethical issues related to autonomy or competency and self-determination that beset persons with developmental disabilities and their service providers. But first a word of caution about language and cultural myth: both have been used to weaken autonomy and self-determination.

Language can be used as a powerful form of stigma. At one time, the correct clinical terms used to describe people with cognitive disabilities were words like "moron," "idiot," and "imbecile." These words are no longer part of our clinical language, but they are still used in hostile name-calling

Ironically, people with cognitive disabilities are vulnerable to being treated with the very thing that is said to be wrong with them in the first place: lack of control over their lives and circumstances.

(Dudley 1997). Apparently, children listen when adults describe their classmates in terms of a disability diagnosis. Later, the children use the diagnostic term as a weapon against the person it was intended to describe, and to tease or put-down nonlabeled classmates.

More recently, people whose diagnosis is "mental retardation" have reported that because the term "retard" has been used against them by peers, retardation is no longer acceptable as a clinical label. The currently "correct" clinical label is "developmental disability" — a more inclusive term, referring to any disability that affects the speech, communication, mobility, learning, self-care, or other ability of a person that is evident (i.e., diagnosed) within the first twenty-two years of life. However, it is only a matter of time before this term, too, will have a stigma attached to it — the usual outcome of any label that refers to a condition of "being (or having) less than others" in some manner.

The linguistic problem is compounded in some circles by a cultural myth that people with developmental disabilities are "too disabled" to be self-determining (Lehr and Brown 1997). However, research has shown that people with even the most profound disabilities have definite

preferences and seek to control their environment. Self-determination, in fact, must be carefully guarded for people with disabilities because they are the ones most at risk for being denied the opportunities, training, and support that are necessary to help them develop the ability to communicate personal choice (Lehr and Brown 1997).

One issue central to perpetuating this myth is the lack of respect that society as a whole gives to people with developmental disabilities. Respect is the regard of another who acknowledges an individual's inalienable right to hold views, make choices, and take action based on one's personal values and beliefs. The principle of respect is central to any conversation about clinical ethics (Reynolds 1998). As William Donovan (d. 1959) wrote, it is impermissible not to regard every human being with respect, as a rational creature. Without the respect of society, there is little protection for one's rights.

In determining a balance of power in the lives of people with developmental disabilities, the competing moral standards are autonomy versus competency. That is, the right of individuals to be self-governing, versus the responsibility of society to care for a member with some area of weakness or incompetence. Ironically, people with cognitive disabilities are vulnerable to being treated with the very thing that is said to be wrong with them in the first place: lack of control over their lives and circumstances (Guess et al. 1985). A brief history of the current system illustrates this tendency.

History of Managing Disabilities in the Community

The present system is built on the past. In the 1830s, Dorothea Dix worked to reform the American system of mixing patients with mental illness among those in hospitals for physical illness. She proposed that homes (i.e., asylums) should be built to offer people with mental illness shelter from the stresses of life on the outside. It was expected that all admissions would be involuntary, since it was then believed that mental illness compromises reason. It was then that the issue of guardianship

first arose, as a means to protect and provide for vulnerable persons.

The first modern asylum was built in Worcester, Massachusetts, in 1833. By 1955, over 500,000 Americans lived in state mental institutions. Gradually, as the number of people receiving care in institutions increased, the zeal of caregivers for reform and treatment declined. Interactions between staff and patients became standardized, with little room for individual preferences and choice. In addition, once the asylums were in place, people were placed in them at very young ages, down to the age of birth. Thus, people were sentenced to spend their entire lives in an institution, despite never having demonstrated an inability to care for themselves or participate in society.

Successful lawsuits challenged the right of the state to imprison those who had broken no law. Then, in the 1970s, the next wave of reform began, when approximately 75 percent of patients in state institutions were released (Pence 1995). By 1988 there were only 130,000 people in American state institutions. As of 1998 about 55,000 people (in forty-six states) were still in institutions (Agosta 1998).

At present, a reported 388,941 people are living in smaller "congregate" settings receiving public funding (Agosta 1998). Many of these people are living institutional-style lives, albeit in the smaller congregate setting. These small, intermediate care facilities (ICFs) for people with mental retardation are often referred to by the acronym ICF/MR. ICFs were believed to be better than institutions because they were smaller, scientifically designed, professionally staffed, and organized according to individual learning objectives or habilitation plans.

After 1967, it was illegal to keep a person in custody without providing what the courts called "active treatment." As a result, many institutionalized individuals were taken lock-step through a set of "learning objectives" (Bradley, Ashbaugh and Blaney 1994), merely to demonstrate that "active treatment" was being pursued for each

person in custody. The objectives or habilitation plans were, on paper at least, customized for each person in custody.

For most people served in the ICF system, the individual habilitation plan was devised to remediate behaviors that were presumed to prevent one from fitting into a community, and to teach skills that he or she would need to live independently. However, these training tasks were often presented to the learner in a regimen without regard for the context in which the activities were taught (Bradley, Ashbaugh, and Blaney 1994), which decreased the generalizability of the skills to other settings. Further, the habilitation plans often called for the satisfactory mastering of each skill before one could move on to the next level of training. This restrictive, isolating, and unstimulating environment failed to consider the views of the very person whose benefit the program was meant to serve.

People living in publicly funded congregate settings have been surveyed recently for life satisfaction. In a 1995 survey of 5,000 mental retarded/developmentally disabled individuals, Wehmeyer and Metzler (as reported in Sands and Wehmeyer 1996) reported the following:

- 66 percent did not chose to be living where they currently were living,
- 88 percent did not choose their staff person,
- 77 percent did not choose their roommate, and
- 56 percent did not choose their job.

But in a sample group of 400 adults without disability:

- only 10 percent did not choose where they live, and
- only 13 percent had no choice in a roommate.

Individual choice or self-determination is quite obviously lacking among those with developmental disabilities, as compared to people in the sample group that had no disability.

The present patchwork of schools, clinics, hospitals, and service agencies represents the

historical metamorphosis of innovation, belief, and reaction. The laws, that diverted the flow of persons with disabilities away from the mainstream and into institutions, has reversed, shifting them into segregated community living. Such laws are milestones, marking the shifts and trends in public opinion.

Institutionalized or in smaller congregate living, people with disabilities are seeking self-determination for themselves at the same level of control exercised by people without disabilities. Questions about self-determination are not theoretical values, which they can pursue as an intellectual endeavor without practical application. The quest for self-determination among people who use support systems challenges those who work with them in the system (in human services) to examine their personal value systems and apply ethical and moral issues to their everyday conduct. Still, even in situations of glaring inequality faced by people with disabilities, something keeps their interests from being recognized. The ethical and moral questions about power, human rights, legal rights, and morality must be answered in the context in which they belong, in the lives of real people (Sands and Wehmeyer 1996).

A Life of One's Own

Sands and Wehmeyer (1996) suggest that self-determination requires reasonably accurate self-knowledge and awareness of one's individual strengths and limitations. An act could be considered self-determined if the individual's actions reflect four essential characteristics:

- the individual acted autonomously,
- the behavior was self-regulated,
- the person initiated and responded to events in a psychologically empowered manner, based on self-realization, and
- the person had identified desired outcomes for the action.

By definition, a person with a developmental disability lacks adequate tools for some specific

behaviors or actions (Nosek and Fuhrer 1992). But Kerr and Meyerson (1987) have previously pointed out that there is no necessary relationship between those missing or impaired tools, and the ability to find creative ways in which to meet the demands of social, psychological, or cognitive tasks. A narrow focus on basic skills misses the point completely: people are much more than the sum of their parts.

Since actions taken by support people on a daily basis affect the lives of the people they support, care must be taken not to abuse the valid use of power. The tendency to make decisions for the person's own good, or because the support person can reach the right conclusion faster, must be strenuously resisted. Those in a position of power should reflect often on the following questions:

- When is a choice bad, versus merely different from one's own choice?
- When is a goal unrealistic, versus merely beyond one's ability or too much trouble?
- When is an activity too risky and irresponsible, versus being a risk worth taking and a necessary part of a person's growth and development?
- Is this decision in the best interest of the person, or in the best interest of someone else?

Consider how these questions might be answered in the case of Amy, an eighteen-year-old with a diagnosis of mental retardation. After graduation from high school, Amy's parents were convinced by professionals that Amy needed to be placed in a nursing home, *for her own good*. Some of the planning meetings occurred without her knowledge. Yet even when Amy was allowed to attend the meetings, staff told her that she was not to speak. So at eighteen, Amy packed her cassette tapes, her fashion magazines, and her glamour posters and moved into a nursing home with seven other women. Her new housemates were fifty-five to seventy years old.

Amy found that the others in her new home were not interested in her magazines, music, or

other hobbies. When weekends came, Amy was forced to attend the sedate recreation favored by her housemates, when she wanted to go to dances and movies with peers. She was not allowed to go on walks with friends from high school, unattended. Her life revolved around going to the sheltered workshop on the nursing home van, and to group outings in the nursing home van with her housemates and their staff.

Amy had been cheery and friendly. In high school she had had many friends. Now she became rude, rebellious, and was likely to burst into tears. People began to suspect that Amy had a mood disorder, and she was referred to a psychiatrist. People began to say she had a mental illness.

Amy's mother had never been sure that the nursing home idea was a good one. However, she did not like to take a stand against professionals who knew so much about what was good for people "like Amy." However, Amy persisted in asking for her mother's help, and at a planning meeting when Amy was nineteen, her mother suggested that Amy move into an apartment with a roommate. As it happened, a staff person at the nursing home was getting divorced, and offered to take Amy as an apartment mate.

At first the staff-become-roommate was very conscientious about taking care of Amy. She selected furniture for the apartment. She made Amy purchase a new bed that she didn't want, since it would make the apartment look better. She even cut Amy's hair short, because she liked it better that way, although Amy was trying to grow it out. Until this woman started dating again, she was an active presence in Amy's day from sun-up to sun-down. Amy seldom saw anyone else. Some months later, however, the woman began going away for weekend dates, leaving Amy on her own from Friday through Sunday.

Being left on her own, Amy learned that she could take care of herself. She began to feel more cheerful. On her own Amy applied for, and got, a job at a fast food restaurant. She got a learner's permit for driving. She picked up her old friendships and made new friends among members

of a local support group for adults with disabilities. Amy had a life of her own choosing. Amy's mother saw how well she was doing, and when the staff decided to move in with someone else, Amy was ready to live on her own.

Now Amy is twenty-three years old. She has learned to use the computer and has her own website. She still works in the same job she found for herself. Her hair has grown out, and she is beginning to wonder if she could take a course at the local community college. Amy feels as though she has had a narrow escape.

One of the myths in the human service community is the belief that the presence of disruptive behavior requires an increase in the control exerted over an individual (Lehr and Brown 1997). In actuality, helping the person gain more control over his or her environment, rather than less, reduces some problem behaviors, as in Amy's case.

The Law and Public Policy

While many people work in the human services for altruistic reasons, the current system is an example of "benevolence gone awry" (Varela 1986). Ethical theory can explain the path of public opinion as it relates to past formulations of ethical responsibility in health care (Beauchamp and Childress 1994). The process has been marked by altruistic efforts to address the needs of people with mental illness or developmental disability who were without places to go, and who were habitually confined to county jails when they became disorderly or vagrant (Applebaum 1994).

However, according to philosopher, Lionel Trilling, altruism creates a paradox. Something in human nature causes the object of enlightened interest and pity to become the object of coercion. There may be a shift in the balance of interpersonal power created by the act of becoming the object of someone's well-intentioned pity. Laws go astray, and well-intentioned laws can actually cause harm (Varela 1986). This outcome is almost certainly the case with laws pertaining to the social welfare of Americans with a developmental disability diagnosis.

Before 1961, few mental health issues generated much fervor in law (Applebaum 1994). Beginning in the late 1960s to 1979, mental health law underwent an intense change. Since 1971, people with mental retardation and developmental disabilities have the right to receive individual habilitation so that each will have a realistic opportunity to lead a more useful and meaningful life in society.

Human service workers, legislators, and society must consider the relationship between the right to habilitation and the right to personal liberties.

Personal liberties include the following:

- The right to accept or to refuse treatment.
- The right to plan one's own affairs.
- The right to shape life as one feels it is best.
- The right to go where one pleases, and do what one pleases, with freedom from restraint (Bannerman, Sheldon, Sherman, and Harchik 1990).

Not only do people strive for freedom in a large sense, but they seek the right to make simple choices, in everyday activities. People cherish the right to plan for themselves and carry out those plans. In public policy there is no question that people are entitled to their civil liberties.

But according to some analysts (Bannerman, Sheldon, Sherman, and Harchik 1990), civil liberties are sometimes compromised in habilitation settings in the following ways (consider Amy's case):

1. The person for whom the plan exists has had little or no input into decisions regarding treatment goals or procedures used to teach them.
2. Plans have been made in accordance with staff preference, rather than with client preference.
3. Informed decision making is not taught as a responsibility. It is, in fact, only permissible at times.
4. Pressure to meet regulatory standards places too much emphasis on scheduling of

habilitative activities, such as hour-by-hour schedules that people have to follow.

Such situations are defended by those who believe that if given the opportunity to be self-determining, some individuals will make *inappropriate* choices, or do nothing at all (Lehr and Brown 1997). The counterpoint is that all individuals, regardless of their disability, have the right to make decisions, both good and bad. If an individual frequently chooses to do nothing, ways of creating a more stimulating and personally rewarding environment probably need to be found.

There are no regulations that prohibit individuals from taking control over their lives. Such an outcome may be more a lack of attention to safeguarding such freedoms, than an intentional act. However, it is the responsibility of those who provide supports for others to do so in a way that creates opportunity for personal growth and the development of self-determining skills.

The essential task for those in human services is to help individuals seek ways to access supports in a manner that creates maximum individual control and minimal disincentives to independent living and creative productivity (Nosek and Fuhrer 1992) because those who begin to move along the path of self-determination are more likely to review their progress critically and make adjustments to increase the effectiveness of their problem solving. The outcome is self-actualization, self-driven development of persons to their highest potential.

Public Morality, Private Lives

In 1859, John Stuart Mills wrote about the "admirable distinction between private life and public morality" (quoted in Pence 1995). A civilized society must promote certain ideals and discourage others. But the power of the nation can be dangerous if used against an individual. In determining where to draw the line between public morality and private life, Pence quotes Mill's Harm Principle. The Harm Principle states that private life encompasses those actions of an adult or adults together that are personal and do not put other people at risk. In private life, as defined by the

Harm Principle, there should be no interference by government even for the person's own good if no one else is affected. Personal life is therefore considered to be composed of the actions that are purely private and affect no one else, while morality is composed of interpersonal actions.

Public opinion, on which common law is based, is formed on society's current interpretation of morality. Morality is social convention about what is right and wrong in human conduct. These beliefs are so widely shared that they form a stable, though incomplete, consensus. A moral dilemma is formed when there are two competing moral standards. No matter which one is selected, the other must be set aside (Beauchamp and Childress 1994).

Recall our earlier assertion that in determining the balance of power in the lives of people with developmental disabilities, the competing moral standards are autonomy versus competency. Then how do we adjudicate the right of individuals to be self-governing without shirking society's responsibility to take care of a member with some area of weakness or incompetence?

What are the person's rights? Rights are justified claims based on a system of rules that authorize people to demand what is due. Legal rights are claims justified by legal principles and rules (Beauchamp and Childress 1994). It should be difficult to revoke a person's civil rights, but society's attitude toward cognitive impairment makes the step short. Many of the people in congregate care are not there of their own choice. They have already lost their civil rights, through a most straightforward legal process: the hearing to establish the competency of the individual or to assign guardianship of the individual to another. This condition is a common result of the old habilitation system.

In discussions about autonomy, the problem of competence only arises if there is a prior question about a person's ability to make decisions and there is no single, acceptable standard of competence (Beauchamp and Childress 1994). Competence must be decided relative to the particular decision to be made. Competence is best understood as specific rather than global. The law has

traditionally presumed that a person who is incompetent to manage his estate is also incompetent to vote, to marry, or to participate in other civic activity. This view is based on a judgment of the whole person, which is gradually becoming known as an overgeneralization.

Assumptions about diagnoses in general, and mental retardation, in particular are in a state of disequilibrium. A close connection exists between law and public policy. All laws constitute public policy, but not all public policies are law. The ethics of public policy come directly from the friction surrounding "impure and unsettled" cases in

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which there is profound social disagreement. These difficult cases bring to light the underlying uncertainties, different interpretations, and the imperfect procedures that have been used to resolve disagreements. This, then, is the current status surrounding the rights of people with cognitive disabilities, both legally and in public policy.

One reason for not respecting the rights of adults with mental retardation, is that they are "not capable of being independent." As Gaventa (1980) said, the most insidious use of power is to prevent conflict from arising in the first place. Myths and misinformation proliferate around the issue of mental retardation. Why should people with disabilities be discredited for not performing tasks that people without disabilities cannot perform? For all citizens, many autonomous actions could

not be brought about without the cooperation and assistance of others (Beauchamp and Childress 1994). Interdependence is necessary among people at all levels of cognitive functioning. Sometimes, an individual must receive assistance to reach a level of understanding that will enable him or her to function autonomously. That person's competency — or decision making should be respected. An example in the general population is that of any individual who is diagnosed with a medical problem, and needs additional information before he or she can choose among various possibilities of treatment. A similar supportive process should be offered to people with cognitive disabilities.

In December 1991, Congress passed the Patient Self-Determination Act (PSDA), which is the first federal legislation to ensure that health care institutions must inform patients about their rights under the law, and their right to accept or refuse medical treatment, and to formulate advance directives. This act demonstrates that public policy is moving toward a standard of self-determination as a civil right, regardless of what the experts recommend. This trend may also have profound impact on the civil liberties of Americans with disabilities.

Competency and Decisional Capacity in Health Care Issues

While tests may measure how close a person's judgment is to the norm and this may be justified, they may also conceal an unduly narrow value perspective (Beauchamp and Childress 1994). Decision makers may perceive the diagnostic label (mental retardation) as discrediting and that competency cannot coexist with disability. Competency is a "point in time" issue. Its determination calls for use of a functional assessment tool that can avoid the vague generalizations that might otherwise be made concerning competencies. It is also probable that many people who originally score poorly on the assessment tool, could benefit from supportive counseling, or other types of discussion on a one-to-one basis to help them make informed decisions. The traditional assumption that a person who is incompetent to manage financial affairs is also

incompetent to vote, marry, and make medical decisions, had more to do with protecting property, than human rights; and laws based on that assumption make a global sweep based on a total judgment of the person that can be carried too far (Beauchamp and Childress 1994).

True decisional capacity is task specific. The person could only be said to lack capacity for a specific decision at a particular time and under a particular set of circumstances. Determination of decisional capacity is not based on a fixed, objective standard, but on the careful, respectful judgment of those who know the person best.

If the patient objects to the ruling, there must be a standard procedure under which he or she can obtain a second opinion, or offer rebuttal (Midwest Bioethics Center 1998).

Decisional Capacity and Guardianship

One reason the determination of decisional incapacity is so serious is that it is very difficult to revoke a guardianship once it has been established. In theory, there is a standard practice for doing so, but once created, there is a presumption that the guardianship was needed. A very strong case would have to be made which showed why a change should be considered.

It should be very difficult to revoke autonomy — one's civil rights — but society's lingering prejudice against people with cognitive impairments has prepared an uneven playing field in which to consider this question.

Where Do We Go from Here?

As previously shown, people with cognitive disabilities have gradually become a disenfranchised pocket in an otherwise freedom loving society. This condition was to some extent the by-product of the pursuit of efficiency. Another reason for institutionalized loss of power for people with disabilities was a belief that sometimes the end, personal safety, justifies the means, loss of decisional capacity (Bannerman et al. 1990). But people with developmental disabilities have also been affected by the low expectations others have for them. Many have a learned sense of

powerlessness that has led to an internalization of the values and myths about disability that have been used to discredit and control them.

A three-tiered approach will be needed to rectify the balance of power in the lives of people with developmental disabilities. Changes are needed in the service system, in decision-making training for people with developmental disabilities, and in the laws that affect decisional capacity determinations and guardianship.

First Area of Change: Service System Change

People seeking the right to self-determination are not asking for the right to make a choice between two offerings, but to have a meaningful voice in planning for their lives. For them, the important components of self-determination are goal setting, problem solving, and self-advocacy (Sands and Wehmeyer 1996).

At present there are three major factors driving change in the habilitation system:

- the grassroots push for self-determination,
- the need for agencies to demonstrate fiscal responsibility and
- a gradual shift in public opinion concerning people with disabilities (Beauchamp and Childress 1994).

The service and support system must be modernized. Bureaucratic requirements have become obstacles to overcome in helping people reach self-determination (Sands and Wehmeyer 1996). Planning must be done with the person, not for the person.

People have the right to be asked, "Where do you want to live and with whom." These are the ordinary, everyday decisions that most Americans arrange to please themselves as a matter of course. However, a person who uses supports has lost much of this autonomy. If they do not willingly comply with others' wishes (the rules) on these and many other topics, they may be "written up," and a "behavior management plan" can be put into place to control them for the convenience of

others. If they still do not comply with the plan that was arranged by someone else, physical or chemical restraints may be used. To avoid punishment, many people obey the various demands placed on them. Think of Amy's story, told earlier in this paper. Without self-determination, a voice of one's own, what is life?

People have the right to be asked, "What do you want to spend your time doing?" Skill limitations and challenges do not mean that a person wants to be "irresponsible" or that he or she refuses to engage in adult decisions and activities. People like Amy are funneled into lives that others find expedient, not lives they have built for themselves. At times it must seem to them that there is no way to exercise control over their lives, except to create

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disturbances for others. This behavior often brings further limitations on their lives, as either punishment or training. The opposite method of response would be far more effective. Broadening experiences, trial and error, creativity, and persistence allow for the development of interests, skills, and competencies. New opportunities follow naturally, as the individual enters new areas and meets new people.

People have the right to be asked, "With whom do you want and need to interact?" Independence is narrowly and rigidly defined in many current habilitation plans. However, interdependence is the true social behavior of humankind. Independent living does not mean having to do everything for oneself, or not having disabilities — it means having control over one's activities. No legal basis exists for treating people with disabilities different from those without disabilities.

Second Area of Change: Training for Life

Training courses must focus on teaching decision making and problem solving to people from the

earliest ages. Self-determination should be one of the most pressing goals of education. Too many people with disabilities remain dependent on caregivers, service providers, and overloaded social systems to do for them tasks they could have learned to do for themselves. Many people fail to reach maximum levels of independence, productivity, inclusion, and self-sufficiency (Sands and Wehmeyer 1996), because they have not had an opportunity to do so.

When people feel that they have power over significant aspects of their lives, they develop a sense of pride and ownership (Hardy and Leiba-O'Sullivan 1998). Empowerment training enables self-efficacy, which is linked to effective performance. That is, empowerment training counters feelings of powerlessness, which are a major impediment to performance (Hardy and Leiba-O'Sullivan 1998). The emphasis of the training should be on communication skill building, goal setting, and problem solving.

Learning how to make good choices and express them effectively requires experience with the

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process of decision making. There are many opportunities that could be used to empower people by teaching them, throughout their lives, to make age-appropriate decisions (Lehr and Brown 1997). It is only by direct experience that people can learn to make choices in a meaningful way, and by following through, to achieve their goals.

Opportunities to make choices, decisions, and express preferences are absent from most educational and training programs for people with disabilities. Current training programs are usually

quite strong in training people to cooperate and comply with directions. One reason that educators and administrators exert a high level of control over the lives of people in their programs is that they fear that their students will make poor choices and be hurt by them. Choice necessarily involves some risk, but the larger question is this: do people with disabilities have the same right to develop autonomy as the rest of society (Guess, Benson and Siegal-Crusey 1985)?

For people without disabilities, decision making begins in infancy with nonverbal communication. The process should not be more limited for people with disabilities. Choice is an expression of autonomy and dignity. The loss of the opportunity to have choice, to experience loss and gain, is loss of a chance to experience accomplishment and self-actualization.

Third Area of Change: Legal Process

Finally, the law must be amended to protect the rights of people with disabilities. Current conditions reflect past practices, before due process by law was required to confine one in a mental institution (Applebaum 1994). The same situation now occurs in the issue of guardianship.

We need to shift the burden of proof to the shoulders of the state, for those who wish to revoke an individual's civil rights by assigning that person to a guardian. To take the devastating step of revoking a person's civil rights, the state should have to prove incapacity. Incapacity should only be adjudicated when it is proven that

- the individual does not have the capacity to understand information relevant to making an informed decision,
- the individual cannot deliberate about the choices in terms of personal values and goals, and
- the individual cannot communicate *at all* with caregivers or others.

Even then, such a decision should be considered temporary.

Among community members there is a wide divergence of opinion as to how much the cognitive and emotional abilities of an adult must be diminished before we conclude that the adult is decisionally incapacitated. It is difficult to determine decisional capacity, because there is no objective standard. People place the line of demarcation in different places, subjectively (Midwest Bioethics Center 1998).

The recent history of determination of decisional capacity has shown that there may be inadequate training and monitoring of health care providers in the practice of determining decisional incapacity. Although they are often used, mini-mental status exams or consulting psychiatrists are not adequate to the complex task of determining individuals' loss of the right to negotiate in decisions that affect them, according to their personal beliefs and preferences. A mini-mental status exam is too brief for the consultant to get in tune with and understand the unique communication style of an unfamiliar client. The Midwest Bioethics Center recommends that only a health care provider who has a long and personal relationship and knowledge of the person is in a position to give an expert opinion (Midwest Bioethics Center 1998).

Once made, the decision must be regarded as a temporary one. The decision stands until the outcome of training, education, and other assistance enables the person to resume autonomy at the earliest possible moment.

Understanding Decisional Capacity

Determination of decisional capacity is an artform. It makes use of a clarifying conversation that involves the balanced assessment of both cognitive and emotional processes and an estimate of the coherence of self-structure in the person's own life story.

The interviewer must learn to frame the conversation in a way that is intentionally accommodating to the patient's perspective. If the patient is accustomed to working with a partner, the partner should be included in the conversation. The interviewer must start with the assumption that the patient has the capacity to decide

rationally. The patient must be told why the interviewer is there, and what decision is resting on the outcome of the conversation. The interviewer must not allow the difficulties the person has with speech, hearing, or other communication influence the outcome.

The person who has decisional capacity will ask relevant questions, show evidence of self reflection, express meaning, concern, and appropriate affect. There will be consistency of the person's own views expressed over time, and across settings. The central question in determining decisional capacity is whether the patient is able, in his or her own terms, to understand the clinical issues involved in the decision.

A change in perspective on capacity is called for, since a focus on the medical aspects of self-

Determination of decisional capacity is an artform. It makes use of a clarifying conversation that involves the balanced assessment of both cognitive and emotional processes and an estimate of the coherence of self-structure in the person's own life story.

determination (i.e., for informed consent and advance health care directives) has encouraged the finding of incapacity in one area to be generalized and applied to another. Health care providers must be trained to be very self-critical when making decisions that affect the civil and human rights of others. They must learn to be aware of their subjective biases and to give careful in-depth evaluation of multiple factors that interact in decisional capacity. Above all, they must learn to recognize a spectrum of developing, partial, complete, fluctuating, and diminishing decisional capacities.

Summary

At present, people with developmental disabilities and their system of services and supports are partners in an unequal relationship. The framework of the relationship is power. Those with the power have, until now, chosen the agenda. The agenda of the people the system was built to serve is, as of now, largely unknown. If those with greater power choose to share it, the balance of power in the relationship may shift. If people with disabilities are given appropriate training, their talents and potential will be unlocked. Training will empower people so that they will be able to take a leadership role in forming a new kind of partnership, a partnership in which traditional care providers and people with developmental disabilities can begin to shape an agenda together.

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