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Abstract

THIS IS A DRAFT AND IS NOT TO BE QUOTED. Written in a polemical, confrontational tone, the authors present a strong argument against paid services for people with disabilities. In this lengthy document, the authors examine the threats to good care for people with disabilities provided by services. They then go on to describe the resistance to radical alternatives to paid services. **Keyword: Community Development**
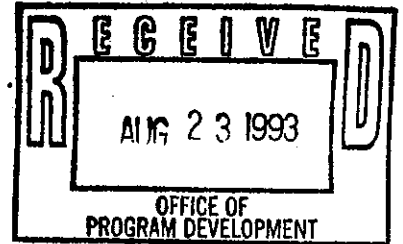
Assistance With Integrity

The Search For Accountability
And
The Lives of People With Developmental Disabilities

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DRAFT

The problems of life are insoluble on the surface...

Getting hold of the difficulty deep down is what is hard.

Because if it is grasped near the surface it simply remains the difficulty it was. It has to be pulled out by the roots; and that involves our beginning to think about things in a new way. The change is as decisive as, for example, that from the alchemical to the chemical way of thinking. The new way of thinking is what is so hard to establish.

Once the new way of thinking has been established, the old problems vanish; indeed they become hard to recapture. For they go with our way of expressing ourselves and, if we clothe ourselves in a new form of expression, the old problems are discarded along with the old garment.

—Ludwig Wittgenstein[†]

† Wittgenstein, L. (1980). *Culture and value.* Oxford: Basil Blackwell, p. 43.

A note on style

This report is written as a polemic, a discussion intended to stimulate controversy and dispute. While this style has an honorable tradition in politics and philosophy, it is little used in the world of human services, where inquiry is mostly shaped by middle-of-the-road academic social science with its conventions of detached objectivity and quantification. Contrary to this more usual style, we will assert strong positions because, based on our experience, we believe them to be true and useful. We have been informed by the meetings and interviews noted on the cover page, but we have not been limited by them. We do not claim to be dispensing objective truth, but only to be telling the truth we can see from where we have been. We welcome thoughtful disagreement and evidence and perspectives we have missed.

This report will be particularly frustrating for people who want to tinker with a few new managerial gimmicks rather than redesign approaches to safety and quality from their foundations. Those who want a few, practical, politically feasible recommendations that, if implemented, will assure the safety of vulnerable people while improving the quality and cost efficiency of the existing crazy mix of services can save themselves an hour's effort and stop now. Of course, we will make suggestions that we think are practical. But we make them tentatively, as an aid to thinking and as an invitation to many small scale experiments, not as a grand program.

This report will seem dangerously naive to people for whom civic life has collapsed into economics: a world in which narrow self-interest provides sufficient explanation for behavior and material reward and punishment provide the only effective motor for policy. For them, our appeal to civic virtue will seem quaint if not disingenuous. But we have met many people deeply concerned about doing the right thing in company with people with disabilities. These people find meaning in struggling to better understand the ethics and the politics of their work lives and they find discussions about compliance with rules and avoidance of sanctions beside the point. We don't want to join the cynical, who reduce everything to greed and power over others, in missing their point. So let the reader be warned: the civic virtue of integrity lies at the center of our argument.

Main points

• People with developmental disabilities rely on a service system which is in a crisis of accountability. Efforts to assure safety and quality have become activity traps which threaten the developments most necessary to improve the quality of community life for people with developmental disabilities. Investments in improving the mechanisms of quality assurance have become at best expensively irrelevant; at worst, they are counterproductive. It is this crisis of accountability that calls on concerned people to surface and reconsider their assumptions about assuring safety and quality (see the summary diagram on the next page).

• The current system is well defended against efforts to rethink and fundamentally reorganize it. Nevertheless, such redesign is necessary.

• Two perspectives contribute helpfully to this reconsideration: a perspective revealed by reflection on the experience of people with developmental disabilities who receive good support, summarized here as effective interdependence; and a perspective derived from systems thinking, which offers some useful guidance to the work of redesign.

• The perspective of effective interdependence reveals the virtue of integrity as the foundation for those developments now necessary to improve the quality of community life for people with developmental disabilities.

• Unfortunately, paid work with people with developmental disabilities has an enduring attraction to abusive, neglectful, exploitative, power hungry, and slothful people. While these people represent a minority of those working at any time, their influence can be devastating if it is not checked. Controlling the anti-social minority requires conscious, powerful efforts by people with developmental disabilities themselves and all those who care about their well being. Such efforts require an effective police power, which presupposes not only the capacity to discover and prosecute abuse and neglect but, at least as importantly, the capacity to strengthen the voice of people with developmental disabilities and the capacity to generate alternative living arrangements and alternative sources of necessary assistance.

• To flourish, the virtue of integrity calls on people to create multiple, various, small scale, self-organizing systems of assistance within a field that is increasingly organized by principled negotiation and shared learning. These two challenges define the leading edge of the work of building safer, more just, more inclusive communities in company with people with developmental disabilities.

Contrasting Responses to People's Vulnerability

Regulate

Inspect & correct

Dominant Assumption: People with disabilities are passive, fragile objects with limited possibilities for personal relationships.

- People's needs can be adequately defined procedurally
- People's safety will result from requiring uniform application of policies by staff in whom the system makes the minimum possible investment; high turnover is assumed
- The way to improve quality is to improve organizational procedures
- There is no important conflict between improving quality and insuring safety by requiring uniform application of impersonal procedures

More opportunities

Risk management

Direction from seeking positive change & dealing with the risks & crises that follow

Emerging Assumption: People with disabilities are choice makers, who are capable of contribution and capable of forming rewarding relationships.

- People's capacities and needs can only be understood in the context of trusting relationships in which other people join them in responding to opportunities, problems and risks
- People's safety will be protected as much as possible through the quality of their relationships with family, friends, and staff and the extent to which they can exercise control of their life circumstances
- The way to improve quality is to invest in people's relationships and learning; quality improves through a variety of person specific actions
- There are frequent tradeoffs between safety and risk as people develop and as agencies and the system learn new capacities

Agency Capacities

- Increase ability to form effectively interdependent relationships under conditions of uncertainty, differences & conflicting ideas, high emotion, & low (initial) trust [in an effectively interdependent relationship a staff person identifies & responds to opportunities, problems & risks]
- Increase knowledge of possibilities, risks, & alternatives
- Money to arrange/provide necessary assistance
- A reliable process for providing everyday & unusual assistance

People have a growing number of alternatives to being/feeling trapped within a single service setting

People have increased capacity to effectively communicate their desires & problems

People have increased ability to negotiate & act along with others (friends, family, advocacy organizations)

System Capacities

Tools, frameworks, assistance, & money to encourage...

...agency openness to outside influence

...agency values, vision, & culture which support integrity: good relationships & positive action

...investment in staff competence & continuity

...resource flexibility

Effective ways to respond to abusive/neglectful situations and patterns of abuse/neglect

A crisis of accountability

Services to people with developmental disabilities face a crisis of accountability. Uncounted thousands of hours of professional time and dollars of scarce public resources pour into enforcement of and compliance with increasingly complex regulations. Administrators and professional advocates join forces to assemble a truly comprehensive set of quality assurance mechanisms and activities. Debate about assuring quality and safety fills the pages of journals and swapping anecdotes about the absurd distractions imposed (and accepted) in the quest for compliance fills hours at professional meetings. In the name of entrepreneurial government, or a commitment to total quality management, system managers convene task forces of advocates, providers, and officials in order to slim and streamline regulations.

With all this activity, it is hard to find anyone who will admit to the belief that the present quality assurance system in fact assures that people with developmental disabilities live safely and in receipt of high quality assistance. But it is equally difficult to find people willing to actively experiment with letting go of the premises and practices that drive the current system ever deeper into counterproductivity.

Most people seem to oscillate between complaining about the quality assurance system's ineffectiveness and loading greater responsibilities onto it. Legislators, state managers, and courts delegate responsibility for improving the quality of services to inspection systems that recurrent scandals demonstrate have yet to prove their ability to even keep people safe. Conscientious inspectors question their effectiveness while at the same time seeking greater influence, either by finding ways to be more helpful to service providers or by requesting stronger sanctions with which to punish them. Representatives of advocacy organizations call for more exacting requirements and more extensive program oversight and justify their demands with accounts of the repeated failures of the existing system of oversight and regulation.

Alongside these debates about the administrative activities of quality assurance, a quiet revolution in the lives of a small but growing number of people with developmental disabilities redefines the terms of accountability. People with developmental disabilities who get opportunities and necessary assistance to grow up in reasonably well supported families, to go to school alongside their non-disabled brothers and sisters, to work productively, to be an active part of the civic life of

their communities, and to live in their own homes undermine the current logic of service delivery and thus the foundations of current activities to assure safety and quality. In new roles in new settings, more and more people with developmental disabilities emerge as having the same desire to author their own lives as anyone else does. So, if the service system's function is to promote human development, policies and practices which assume that people with developmental disabilities are passive objects of professional work must change.

People with developmental disabilities cannot survive and deal with the many serious life problems in these new settings without effective assistance. The strategic challenge now facing policy makers and practitioners lies in learning how to increase opportunities and focus assistance effectively on a growing variety of individual circumstances.

These pioneers and their allies set the test for every policy and service strategy, and so for any approach to assuring safety and quality. The test is simple: does this activity increase service capacity to assist people with developmental disabilities in expanding their opportunities to participate in community life as they choose?

The dominant share of existing policies and services respond to a different strategic test: does this activity increase capacity for the proper performance of bureaucratically specified professional work on people with developmental disabilities? Under this strategic challenge, activities to assure safety and quality focus on improving control of the professional work assumed necessary to repair (habilitate, rehabilitate, train) defective people. In this world, bad things happen to people with developmental disabilities because of shortcomings in professional work, such as inadequate supervision or inappropriate selection of therapeutic techniques, or poor hiring practices, or failures of audit and inspection..

The crisis of accountability cannot be resolved by a successful search for more efficient means of monitoring or better techniques for insuring compliance. The crisis goes deeper than that. To find our way out, we must question in practice the fundamental assumptions underlying policy and management in the field. Any approach to assuring safety and quality based on an image of people with developmental disabilities as passive, deficient objects is not just inefficient but counter-productive. Every dollar invested in such activities is worse than wasted because it misdirects attention, time, and money away from the crucial changes

in mindset and practice that will make services accountable to the changing realities of the people who rely on them.

	Dominant Pattern	Emerging Pattern
Strategic Challenge	Increasing the availability of professionals to work on changing people with developmental disabilities in bureaucratically managed settings.	Expanding opportunities and assistance for people with developmental disabilities to participate in community life as they choose.
Image of person with a developmental disability	Passive object of professional work. Passive victim of professional neglect.	Author of own life, given opportunity & assistance. Vulnerable participant in conflicts. Potential victim of abuse, neglect, or domination by disrespectful others
Contribution of quality assurance	Assure correct performance of professional work through bureaucratic control.	Promote and disseminate learning from action to increase opportunities for people with developmental disabilities.
Means of assuring safety & quality	Detailed specification of procedures, outcomes, & documentation in legal regulations. External inspection by professional inspectors (perhaps supplemented by panels of 'lay' monitors). Identification of deficiencies in professional work leading to required plans of correction. Administrative sanctions for non-compliance, typically involving threats of loss of funds to serve people or fines.	Strengthen the voice of people with developmental disabilities & their families & friends. Increase capacity to generate new, personalized living arrangements. Develop effective police power to detect, investigate, & prosecute abuse. Enforce contracts to avoid neglect. Negotiate contracts with providers to systematically redirect service capacity to increase community opportunities & to provide focused assistance. Invest in strengthening learning capacity .

Redefining accountability in terms of the emerging pattern described above is fundamentally a political activity. The many involved stakeholders will need to search together for ways forward. Their search will have to overcome conceptual and emotional barriers, as well as structural and political problems.

Two perspectives can contribute helpfully to the search for accountability. One, which specifies the key to accountability in the emerging pattern, derives from the experience of people with developmental disabilities who have good support. The other originates from the developing field of systems thinking and provides some useful guidance for the process of redesigning approaches to safety and quality.

After naming some of the barriers to thinking deeply about issues of accountability, the remainder of this report briefly explores guidance from systems thinking and develops a perspective on safety and quality from the experience of people with developmental disabilities.

Barriers to thinking deeply about accountability

*Thought Experiment**

At least two states have made substantial efforts to revise their regulations. In both cases, state managers responded to vigorous and sustained complaints that providers were over regulated, and a key goal of the process was to increase local flexibility by streamlining regulations. In both cases, state managers announced willingness to put everything on the table for reconsideration and, if necessary, to work for legislative change or to negotiate with federal funders for changes that would make services more individually responsive. In both cases the work was done by task forces with members representing advocates for people with developmental disabilities, service providers, and involved state agencies. There were ample opportunities for consultation and public comment.

Thought Experiments embody some of the puzzles we have found in our exploration of work to improve the safety of people with developmental disabilities and the quality of the assistance they receive. We don't think these puzzles can be answered unequivocally; at least we can't answer them. We do believe that considering them thoughtfully will help to build the new ways of thinking necessary to taking the next steps toward better lives for people with developmental disabilities.

In both cases, the result was as many or more requirements on service providers than existed before the streamlining process began. In both states, providers continue to complain that regulations make it impossible to serve people as effectively and efficiently as they would like. Even those providers who were personally involved in revising the regulations, and strongly argued for including most of the provisions of the revised regulations, join in the complaints.

What accounts for the ironic results of these two efforts at decreasing regulation?

Clichés which block thinking

Each time people are tempted to let go of existing regulatory behavior, at least six clichés recur to tighten their grip on dysfunctional, but familiar, ways. Like all clichés, these reveal a part of the truth while relieving the speaker of the burden of thought and the threat of change.

- *Some providers are just plain bad.* There are persistently abusive or exploitative or neglectful or dishonest people who provide execrable services to people with developmental disabilities and defraud the public. Without adequate police power it would be impossible to rescue their victims. It is easy, though superstitious, to link the need for effective authority with the existing structure of regulations, inspections, and plans of correction. ("Wittgenstein (the person quoted on page 2) can talk about getting to the roots of things, but while he philosophizes, people are at the mercy of unscrupulous operators.")

- *The public expects regulations.* Bad things will happen to people with developmental disabilities, as they will to people without disabilities. Although many of these incidents will be tragic accidents, some reporters and some politicians project great faith in regulations and oversight as a sufficient means to prevent bad things from ever happening. If something bad does happen, some service provider must have broken a rule and some bureaucrat must have failed to take notice of the infraction. If no rule appears to have been transgressed, someone is responsible for the failure to make a rule. No one relishes the thought of public responsibility for removing any possible protection. ("How would Wittgenstein like to explain to Mike Wallace on 60 *Minutes* that he took away a rule against something somebody has been caught doing?")

- *Inspectors are good people.* Many inspectors are fine, dedicated, capable people. Most all inspectors occupy civil service positions, which vigilant legislative analysts would be happy to delete at the first hint that they are unnecessary. Most inspectors have identified some serious problems and many have made contributions that service providers appreciate. It is hard to talk about redesign without threatening inspector's livelihood and self worth. Their response to this threat is likely to highlight, if not exaggerate, the negative potentials in the system and their ability to overcome them. ("If Wittgenstein had seen what we have seen, he wouldn't be so quick to talk about doing away with the inspectors whose positions we have worked so hard to establish.")

- *The health department and HCFA and Congressperson _____ all say we have to do it.* Over the past twenty five years, the developmental services system has systematically shifted funding away from local and state tax revenues and toward cost sharing with the federal government, chiefly through the medical assistance program. In many states this splits responsibility for quality assurance between state agencies, and in all states it makes the federal medical assistance bureaucracy a significant actor whose idiom is regulatory process. Fears that change will lead to loss of expanded federal funds, federal audit exceptions, demands for pay-backs, and the shameful end of careers in public administration drives people at all levels to read the minds of the people who regulate the system: "The change seems reasonable to us, but HCFA will never allow it, so lets forget it." Scandal in one part of the country can lead influential members of congress to generalize their staff people's ideas of remedies to the whole system. ("Wittgenstein never had to face a federal look-behind audit.")

- *Without regulations, service providers won't improve.* Regulations have become vehicles for positive aspirations, such as the provision of well coordinated, individualized services. A form of magical thinking inflates the power of regulation and leads people to speak as if changing regulatory language would necessarily deprive people with developmental disabilities of substantive benefits which they now actually enjoy. Thus people recoil from the suggestion that case management requirements be simplified or eliminated when they know that case managers are overcommitted to the point that they have only perfunctory involvement with most of their clients. And people who personally embrace positive commitments say that regulations must remain strong to

keep other people in line, even though they are not necessary for them. ("Doesn't Wittgenstein want people with developmental disabilities to have good services and good lives? If rules don't require coordination, there won't be any. Of course, we'd cooperate, but no one else would.")

- *People may complain, but they really like rules.* Current regulations define important boundaries in the existing service system. They offer some leverage to professional advocates, they provide some justification for requests for greater service system funding, and they may set some limits to liability. There are very significant sunk costs in compliance with existing rules (including hundreds of millions of dollars of capital expenditures on congregate, segregated service settings and years of specialized training for such professional hybrids as the QMRP (Qualified Mental Retardation Professional)). Existing rules also give service providers, family members, and politicians reassurance that they are doing the right thing, and proposals to fundamentally change them raise the threat that they have done the wrong thing. Last, but not least, they offer a convenient excuse for avoiding change. ("Wittgenstein is wasting our time; too many people have a stake in the current pattern of regulation to ever change it. He should get real.")

Dealing with these clichés challenges the leadership of people who want to explore new ways to assure safety and quality. The clichés are rooted in a history of cynicism and distrust among the stakeholders in the service system. Cynicism about declared public purposes for services can be justified by repeated legislative failures to back positive intentions with commensurate authority and expenditure, and cynicism about the motives of those who provide or advocate for services can be justified by occasional, but undeniable scandal, and the obvious self-interests of service providers. Distrust can be justified by innumerable examples of screw-ups, sell-outs, betrayals, fiscal improprieties, and outright abuses of people. Unfortunately, cynicism and distrust unleash self-fulfilling dynamics. Structuring the search for greater accountability will require people to test the grounds for cynicism and distrust with new and different kinds of agreements. This demand to build trust may be enough to keep the field chronically in a crisis of accountability.

Conceptual discontinuity as a barrier to thinking

A deeper barrier to careful reconsideration of the means to pursue safety and quality lies beneath the defenses offered by these clichés. It consists in the novelty of understanding people with developmental disabilities as whole persons, deserving assistance to author their own lives.* To bring this challenging discontinuity into focus, consider this brief historical sketch.

In the US, the search for accountability began in the mid-19th century, as soon as publicly funded institutions did.† From their first annual reports onward, the social reformers who founded services sought ways to...

...justify increasing public expenditure on the work they were convinced was right

...design physical environments to support their therapeutic aims

...hire, train, organize, schedule, and supervise the assistants and attendants who would carry out their regimen correctly and humanely

...deal with their failures

These concerns, and an underlying view of people with developmental disabilities, have largely defined the terms of the search for accountability until now. The function of accountability mechanisms, from 19th century annual reports to modern certification procedures, is to justify professional work to legislative bodies and thus expand its scope through increased expenditure and increased professional authority. Though the forms of justification vary with changing social climates and fluctuating levels of public interest, the position of people with developmental disabilities remains constant. Whether the administrator's intent is to educate them or to segregate and control them at minimal state expense, people with developmental disabilities are viewed and treated as other than, different

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* See Margolis, H. (1987). *Patterns, thinking, and cognition: A theory of judgment.* Chicago: University of Chicago Press for an interesting discussion of the barrier of novelty to accurate perception and informed judgment.

† See Ferguson, P. (1988). *Abandoned to their fate: A history of social policy and practice toward severely retarded people in America: 1820-1920.* Doctoral dissertation, Syracuse University, Syracuse, N.Y. and Graney, B. (1979). *Hervey Bacus Wilbur and the evolution of policies and practices toward mentally retarded people.* Doctoral dissertation, Syracuse University, Syracuse, N.Y. Ferguson's discussion of the invention of chronicity as a means of dealing with persistent professional failure is especially enlightening.

from, and less than their keepers and therapists. Whether seen as dangerous, pitiable, trainable, or victimized, the role of people with developmental disabilities is to follow the prescriptions of those in authority over them; that is, anyone apparently less disabled then they are, who claims the authority to tell them what to do.

Justifications for this treatment vary depending on social climate. In times when the public mission of services emphasizes the discipline and control of the unruly poor, keepers assert that people with developmental disabilities must be obedient because they are a burden on public charity. The best interests of the state are served when services discharge this burden at minimum cost and in a way that discourages others from adding to the public charge by seeking assistance. In times when the public mission of services emphasizes the therapeutic, professionals say that people with developmental disabilities must obey for their own good. They, and their families, will do better when they follow the directions of professionals who know better. State costs of therapeutic services will be minimized when clients accept their duty to follow the prescribed regimen that will make them less costly as they acquire the skills to become independent. Whichever set of terms is most common at a given time, the other set is close by. Many keepers also assert the therapeutic benefits of their discipline and many therapists also acknowledge that both their clients and the costs of service would run amok without firm controls.

Oddly, the last thirty years emphasis on the rights of people with developmental disabilities seem to have had little impact on the terms of the search for accountability. Perhaps this is because both litigation and legislation have largely accepted the common assumptions of the field. Advocates publicly diagnosed horrible institutional conditions as caused by the triumph of custodial over developmental impulses. The remedy thus becomes obvious: replace keepers with many disciplined therapists whose work is orchestrated by an individual habilitation plan, and replace cheap and squalid warehouses with much smaller and more dignified therapeutic environments, whose increased costs will be reclaimed by the cost reducing performance of newly skilled clients. Advocates publicly diagnosed denial of education as lack of access to professionally composed and implemented individual education plans, and the due process machinery necessary to insure the proper exercise of professional judgment. While significant benefits have come to many people with developmental disabilities

through the success of these efforts, their very success reinforces the position of people with developmental disabilities as the objects of professional work. One can be accorded one's full rights to due process and enjoy all of the benefits of a team planned IHP while asleep or comatose; this is both the strength and the limitation of much current work for people's rights.

Even the principle of normalization (and its partial successor, social role valorization), arguably the most carefully elaborated theory of service reform, presents people as victims of wounding experiences which are mitigated by professionally directed efforts to enhance the image and the personal competence of people with developmental disabilities. The valuable lessons of this theory have motivated and guided many constructive service reforms. But, within the theory, people with disabilities remain, for the most part, in passive roles, either benefiting from correct treatment or suffering from devaluing treatment at the hands of professionals.

The quiet revolutionaries who daily find their way through the economic and civic life of their communities and come home to unlock their own front doors daily overturn the logic of the past 160 years. This is particularly true when they rely on a personal assistant to turn their key or a co-worker to guide them in mastering a new task.

Story has it that the authorities who disapproved of Galileo's ideas about the movements of the planets refused to look through his telescope in order to see for themselves. They already knew what wasn't there.

People with developmental disabilities can ill afford our collective failure to look carefully and think deeply about the emerging experiences of people with developmental disabilities who have new opportunities and reasonable support. But such a look will fundamentally challenge our habits of understanding and action. Inability to assimilate this discontinuity may be enough to keep the field in a chronic crisis of accountability.

Effective interdependence as an emerging perspective on the search for accountability

Growing differences separate the everyday life experiences of people with developmental disabilities. Some people once institutionalized as hopelessly incompetent now have the assistance they need to participate in everyday life, and deal

with life's ups and downs; others remain buried in institutions, large and small. Some people once hidden as shameful and assumed to be socially unacceptable now count ordinary citizens among their neighbors, school and work mates, and friends; many others remain isolated. Some people professionally diagnosed as incapable of meaningful communication and choice now make their individual and collective voices heard; others remain silenced.

These palpable differences in life experience can not be explained by differences in ascribed level of disability, though this mistaken common sense explanation hangs on persistently. And, while competent technical help of the sort provided by experts in instruction, communication, mobility, and personal problem solving clearly matters, professional work does not, by itself, produce these differences. These result from different kinds of relationships among people with disabilities, their families and friends, their service providers, and their fellow citizens —relationships built on the realization of common humanity.

Realization that people with developmental disabilities have the same sorts of needs and aspirations as anyone else usually leads to recognition that they are systematically disadvantaged by socially devaluing practices which are so common that they are almost automatic. When this recognition engenders commitment to join with disabled people in order to resist discrimination and work for justice in everyday settings, effective interdependence grows.

Working for justice in everyday settings only occasionally involves the machinery of formal complaints or the drama of direct action. Confrontations are often indirect, even gentle —as when a person with a developmental disability and her assistant arrive to look at an apartment offered by a landlord who begins the conversation by speaking to the assistant about the disabled person and ends up, effectively redirected, sharing a joke with both of them, or when an employer is encouraged to figure out a job adaptation by a job coaches' question, or when a probate judge faces a man who has, at his own initiation and with his residential support worker as scribe, "Written down here twenty-seven good reasons why I should now make my own decisions and my guardian should be fired. She did a good job of being guardian and I like her, but I don't need her and I don't want her as the boss of me."

When forced into dependency or isolation, people with developmental disabilities wither into the stunted social roles which reflect common prejudices. They

become no more than clients to be processed, passed over, or pitied. Effective interdependence differs importantly from both dependency and isolated independence. A woman with cerebral palsy spells out the difference this way, "Dependency: just doing what I'm told —goes noplace, no fun! Isolation: having to do it alone —can't do much. Interdependence: figuring out what we can do together —nobody can say how far we can go!"

The qualities of effective interdependence

An interdependent relationship incorporates at least two viewpoints. The discussion here will mainly explore the qualities of effective interdependence from the point of view of those who offer assistance. This is because we think that the legitimate purpose of safety and quality assurance mechanisms is to guide the contribution staff make to these essential relationships and not to directly regulate the behavior of people with developmental disabilities.

Over and over again, people providing the assistance people with developmental disabilities need to open up new opportunities return to the same themes as they discuss their work.

• A job coach, "Lots of people with developmental disabilities want to work so they can enjoy the same rewards for being productive that I do. They deserve a fair chance to work and learn from their successes and their mistakes. But the deck is stacked against them: employers haven't had the chance to consider hiring them and lots of employers are afraid because they don't know people, only stereotypes; people's wishes and dreams have been ignored, or even punished, by service providers, so their self confidence has taken a beating; people haven't had much chance to learn real job skills or figure out how to get along with the many kinds of people they meet at work; and people's parents are scared that they'll be hurt and that their benefits will get screwed up. That's where I come in. My job is to help people figure out the way through all those barriers."

• A supported living worker, "All she wants is to be in control of her own life and to keep the apartment she loves. That sounds simple, but about a million problems keep coming up to threaten her; she has so little to fall back on that little problems can get very big. It's up to me to keep the problems as little as possible. Even though she can now manage most all the everyday things for

herself, I'm in it with her for the long haul as far as the out of the everyday problems are concerned."

• A case manager, "They thought hard about their decision to have a child. We talked and talked about it and finally, between them and the grandparents and our agency, we figured out a way to provide just the support they needed. Now someone (we think a nurse at the public health clinic who gave the baby a shot) has called protective services. We're sure there is no question of neglect, but we've got some educating to do -and we have to be sure that everybody stays calm and keeps on track."

• A psychologist, "In the institution he seems to have learned that the only way to have any control was to be really disruptive and angry; to kick and hit and throw things. We have to figure out how to show him that we are on his side; that we want to know his preferences and that we'll do our best to help him get them. Until we earn his trust, things will be pretty rocky for all of us."

These relationships share several important characteristics. Staff people...

...demonstrate respect and active concern for the person's interests and desires by making them the focus of their work.

...appreciate the ways a person's disability and a person's unique history affect everyday life and focus on offering or arranging practical assistance to deal with whatever problems arise.

...recognize barriers in discriminatory treatment perpetuated by service system procedures and community member's habits and put themselves on the person's side in confronting these problems.

...know that a person may well need some assistance for extended periods of time.

These relationships seem far more collaborative than therapeutic; staff skills matter, but in the context of a shared goal. As one professionally trained staff person put it, "Before, in the activity center, I did special education on the clients. Special education was what I was there for: my relationships with people were a way to make my skills work better. Now, as a job coach, I use my instructional skills all the time, sometimes without even thinking about it. But my skills aren't the reason I'm there. My agreements with people who want jobs are the reason