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ABSTRACT

This policy bulletin addresses the issue of protecting the safety of people with developmental disabilities from their increased risk of neglect, abuse, and mistreatment. An article by Steven J. Taylor considers "The Paradox of Regulations," noting both the protective effects of regulations and their effect in stifling innovation and creativity and undermining normalization and community integration. The article contends that regulatory reform depends on reform of the current developmental disability service system, that people with developmental disabilities and their families should be provided with clear-cut rights and due process mechanisms, and that informal mechanisms to promote the quality and responsiveness of services should be encouraged. The remainder of the issue contrasts two approaches to increase people's security. One, which is called administrative regulation and related legal advocacy, formalizes the relationship between people with disabilities and service providers. The second, called lifesharing and other personal commitments, calls for and relies on personal commitment in building communities and protective relationships. Contributions, limits, and effectiveness factors are listed for each approach. Specific recommendations address empowering families, reducing isolation, making services more effective, and supporting the contribution of families and friends. Twelve steps to reduce regulatory excess and encourage quality are listed. (Contains an annotated bibliography of 13 items.) (DB)

FOR THE STUDY & PROMOTION OF OPEN SETTINGS

THE CENTER ON HUMAN POLICY

Research and Training Center on Community Integration
Center on Human Policy, School of Education
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SAFEGUARDS

THE QUESTION

The question--What can we count on to make and keep people safe?--frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives. It arises from a realization of the vulnerability to neglect, abuse, and mistreatment risked by people who require substantial, long-term assistance to take and keep their rightful place as citizens. It is shaped by a sober recognition of the shortcomings of unregulated relationships between people with disabilities and their caretakers and the limitations and ironic effects of systematic efforts to keep people safe through professional, bureaucratic methods. Left to their own services, a frightening number of care providers act inhumanly. But increasing investments in formal means to regulate these relationships don't proportionally increase confidence in people's safety. Indeed formal systems seem to weaken the spirit of commitment necessary for caring relationships to thrive. Discussion is animated by acknowledgement of the desirability and necessity of action to increase people's safety by both strengthening the ties of community and making necessary assistance more relevant and effective.

To increase safety
  *Strengthen community
  *Improve needed assistance

Efforts to ensure the safety of people who rely on services have an instructive history. Many of today's approaches to improving quality through policy, training, hands-on management, and external monitoring would be familiar to nineteenth century asylum keepers. Then, as now, their insufficiency raises a troubling issue. Can it be that the very design of well-managed settings that meet every need frustrates our attempts to embody our good intentions? Could it be that the community services we have carefully developed share too many characteristics with earlier, now discredited approaches? And if so, must people with developmental disabilities accept the built-in limits of total environments as the best available compromise in a dangerous world? What strategies offer ways to constructively engage these questions?

The Paradox of Regulations

Steven J. Taylor

There once was a time when there were few rules and regulations governing the field of mental retardation. The institutions were essentially out of sight and out of mind, and their terrible conditions and abuses represented the field's dirty little secret. Then came the 1960s and the 1970s and the seemingly endless exposes of institutional conditions, law suits, and legislation designed to protect people with mental retardation from the abuses they were suffering. Now, it seems, almost everything in the field of mental retardation and developmental disabilities is subject to rules and regulations.

The regulatory environment surrounding services for people with developmental disabilities stifles innovation and creativity, places undue emphasis on paperwork at the expense of quality of services, and undermines normalization and community integration. The Medicaid program is one of the primary culprits in contributing to regulatory excess in the field of developmental disabilities. The Intermediate Care Facilities for People with Mental Retardation and Related Conditions (ICF/MR) program, other Medicaid programs (day treatment), and even the Medicaid Home and Community-Based Services Waiver program are highly regulated and threaten to remove the heart and soul from community services. Medicaid, however, is only an extreme example of overregulation of services. Many states have developed regulations that exceed federal requirements and impose rigid rules on nonMedicaid-funded services, such as family supports. The major class action law suits of the 1970s and 1980s undoubtedly played a major role in transforming service systems from an institutional to a community-based model, but left a legacy of strict monitoring for compliance with impersonal standards based on a presumption of abuse and neglect in institutions and community programs alike.

The impact of regulations in the field of developmental disabilities is so pervasive that it extends beyond the boundaries of the service system itself into the domain of the community. In some instances, state agencies have attempted to impose regulations on nonfunded "life-sharing" arrangements and threatened to professionalize unpaid roommates and friends of people with developmental disabilities.

So, the question to be asking is not "Are services overregulated?"--because this seems like a foregone conclusion--but rather, "What should we do about over-regulation given the historical pattern of abuse and neglect?" In the remainder of this article, I argue that regulations are paradoxical by nature and counter-productive to the achievements of their intended goals.

***Regulations in the field of developmental disabilities represent the bureaucratization of values.** The problem with rules and regulations lies not in evil intentions and narrow vision of those who promulgate them or in the insensitivity and ignorance of those who monitor their compliance, but in the bureaucratic nature of the regulations themselves. No matter how noble or humanistic the values underlying rules and regulations, the process of bureaucratization distorts those values and makes it less likely that they will be fulfilled. As Blatt (1981) wrote, "Surely there can be no doubt that if 'Love thy neighbor' were a federal regulation, it would become meaningless and useless" (p. 346).

***Regulations reflect the abuses of the past, and sometimes the present, but circumscribe the potential of the future.** The rules and regulations governing the field today are an outgrowth of institutional abuse and are designed with institutions in mind. For every form of evil and abuse that has been found at institutions, someone has come up with a rule or regulation to address it. Regulations are not without their rationales. When taken out of the institutional context, regulations lose their rationality. Regulations presume the impersonal, hierarchical, and bureaucratic structure of institutions. The further removed from this structure, the more irrational and counterproductive they become. Herein lies the paradox: In order to meet the regulations, a setting or a home must become impersonal, hierarchical, and bureaucratic, and these are some of the features that made institutions dehumanizing and abusive in the first place. As the field tries to move toward more person-centered and less institutional approaches to supporting people with developmental disabilities and their families in the community, regulations threaten to drag it back to the institutional model. It is a bit like subjecting home-cooked meals to the same rules that govern fast-food restaurants. This is the surest way to destroy the home-cooked quality of the meals.

***Regulations are best suited to unnatural environments but encourage investment in those environments.** The more unnatural the setting--the more it departs from typical home and family life--the more highly regulated it should be, at least at face value. Because institutions represent the most extreme form of unnatural settings, it follows that they should be subject to the most stringent regulatory requirements. Regulations and institutions seem to deserve each other. The closer any setting approximates an institution, the more highly regulated it should be. This leads to yet another paradox of regulations in the field of developmental disabilities: the more highly regulated a setting, the more resources it requires, and the fewer resources that are available to alternative settings.

***Regulations foster ritualistic compliance and not fulfillment of their spirit.** The more rigid the rules and regulations, the more compliance with them becomes an end in itself. Institutions and ICFs/MR become consumed with demonstrating compliance with the active treatment provisions of federal regulations, and the goals of active treatment take second place. Paperwork becomes synonymous with programming and looking good replaces doing good.

***Regulations place control and power in the hands of regulators, and not people with developmental disabilities and their families.** People with developmental disabilities and their families are often called "consumers" of services, but they are actually third parties in transactions between funders, with their funds and regulations, and public and private agencies, with their programs and services. Rules and regulations, whether imposed by federal programs, state agencies, or courts, place regulators and monitors as the guardians and protectors of people with developmental disabilities and their families and, in so doing, deprive them of control over their own lives.

***Regulations direct attention to concrete and tangible things and trivialize the most important things in life.** A final paradox of regulations is that the most important things in life are the most difficult to measure objectively. As a consequence, regulations place undue emphasis on tangible things, such as the number of square feet per bed, and trivialize the most important aspects of services. Active treatment comes to be equated with paperwork, rather than the quality of programming. This is why dismal programs with good policies and plans can attain certification and good programs with insufficient paperwork can be cited for deficiencies.

Regulations are often criticized for their narrow focus on the medical and treatment aspects of services to the exclusion of community integration and normalization, or social role valorization. Some states are actually moving to incorporate integration and normalization into their regulatory schemes and to require agencies to implement "outcomes"--oriented data-collection systems. Because regulations emphasize tangible things and trivialize important things, such schemes are doomed to suffer from the same problems characterizing other regulations.

If regulations represent a paradox, what are the lessons for regulatory reform in the field of developmental disabilities? First of all, **we need to be modest in our expectations of regulations.** In view of the historical pattern of abuse and neglect of people with developmental disabilities in institutions and other settings, regulations are a necessary evil to contend with evils in the world. Because of their inherent limitations and counterproductive effects, however, we cannot expect impersonal rules and regulations to produce quality services or decent lives for people with developmental disabilities, and, in fact attempts to do so may actually have the opposite effect. Regulations should be kept to a minimum and confined to concrete health, safety, and related issues.

Second, **regulatory reform will depend on reform of the current developmental disability service system.** The current regulatory framework is an outgrowth of a service system dominated by institutions and agency-owned and operated facilities. As long as people with developmental disabilities remain in institutions, community ICFs/MR, group homes, and similar settings, these facilities should be subject to regulations. If, however, the service system and funding mechanisms shift to subsidies and voucher approaches for people with developmental disabilities and their families that place control directly in the hands of those who receive services, the need for regulations will be greatly reduced.

Third, **as an alternative to the current regulatory framework, people with developmental disabilities and their families should be provided with clear-cut rights and due process mechanisms through which to exercise those rights.** Despite its shortcomings, P.L. 94-142 contains vastly superior protections to the highly regulated ICF/MR program. If people with developmental disabilities and their families can act on their own behalf as opposed to depending upon regulators and monitors, then disputes within the service system can focus on important things rather than the superficial aspects of services.

Finally, informal mechanisms to promote the quality and responsiveness of services--agency self-evaluations, consumer surveys, self-advocacy, citizen advocacy--need to be supported and encouraged. These are not a substitute for formal mechanisms in all cases, but in the long run stand a better chance of achieving quality of services or life.

Many states are experimenting with more flexible and responsive approaches to support children and adults with developmental disabilities in the community, and even some recent federal court orders have incorporated them. These approaches hold great promise, but it remains to be seen whether they will fall prey to the regulatory excesses dominating the field today.

Reference

Blatt, B. (1981). *In and out of mental retardation.* Baltimore: University Park Press.

This is a revised version of an article that appeared in *Mental Retardation, 30*(3), 180-195.

SOME FACTS ABOUT REGULATIONS AND QUALITY

- **Quality cannot be mandated.**
- **There are no guarantees of quality in any service system.**
- **Multiple approaches, including informal approaches, offer the best promise in striving for quality.**
- **Regulations and quality assurance procedures developed for traditional services are inappropriate for individualized, person-centered or family-centered services.**
- **Regulations limit flexibility and can interfere with the attainment of quality.**

ABOUT THIS BULLETIN

This is the third in a series of Policy Bulletins presenting information based on and summarizing research findings relevant to federal and state policy on community integration for people with developmental disabilities. These Policy Bulletins are sent, free of charge, to people involved in policy issues at the national and state levels. They are available, for a fee that covers the cost of copying and handling, to others who write for copies.

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Constrasting Approaches

by John O'Brien and Connie Lyle O'Brien

Selecting reasonable action to increase people's security implies more than a choice of tactics. Two different approaches require consideration.

One approach, which we call "Administrative Regulation and Related Legal Advocacy," formalizes the relationship between people with disabilities and those who provide assistance to them. This approach codifies expectations in statute, regulation, and policy, or--if these fail--in judicial decree. The system values compliance and rationally planned improvement in standard and practice. Judgements about the adequacy of response belong to professionals, with a variety of due process mechanisms to resolve conflicts.

The second approach, which we call "Lifesharing and Other Personal Commitments," calls for and relies on personal commitment. People choose to build intentional community or protective relationships with one another. People value the struggle to live creatively in fidelity to the spirit of their commitments. Judgements about quality of shared life depend on mutual trust and listening among those who share a commitment.

Each approach offers something different, but the two mix poorly. Compliance undermines the spirit of commitment. Fidelity depends on trust and breaks down without personal identification and shared values. See pages 6 and 7 for depiction of these approaches.

ADMINISTRATIVE REGULATION & RELATED LEGAL ADVOCACY

CONTRIBUTIONS

Allows rapid change. Some things can be done "with the stroke of a pen."

Permits broad, uniform movements in policy.

Can send strong signals about system direction.

Can shape the common sense of what is unacceptable.

Can shape the common sense of what is possible and desirable.

Can clarify what is in people's best interest.

Does not require waiting for public attitudes to change.

Offers public debate of difficult questions; can improve understanding by insuring that different points of view are heard and assumptions and conclusions are challenged.

Offers leverage to increase vulnerable people's power to seek fair treatment in specific situations.

Can be used as a way to push new issues or start new initiatives.

Offers a way to bring people to the table to negotiate with one another.

Encourages people that something can be done; that progress is being made.

LIMITS

Adversarial relationships, necessary for proper procedure, may harden, pushing apart people who need to work together to achieve results.

Regulations are infrequently written by those most affected. The people closest to the situation typically have to rely on others who are experts in procedures to speak for them.

Regulations limit flexibility--and provide an excuse for inflexibility. There is limited allowance for difference in individual situations.

Regulations can be used on people with disabilities to maintain and extend the power others hold over them. They can be used to justify practices that are against the best interests of a person with a disability.

Regulations are often very hard for people with disabilities to understand.

Procedures for insuring fairness can get complicated and take a very long time.

Because regulations have to take account of the interests of several different groups, they can represent a compromise on what would be best for people with disabilities. They can represent what the regulators think they can get people to do rather than what they think is best.

Regulations can be hard to change, even when people agree they don't work well.

Money isn't necessarily attached to regulations. Providers can be asked to do things without enough money to do them. And providers that don't live up to regulations can still go on getting money and keeping people.

There are things that are important for people with disabilities that others can't be required to do.

Changes in words in regulations can make some people think that things are really different for people with disabilities. This isn't always true.

WHAT CONTRIBUTES TO EFFECTIVENESS?

Insure periodic review that accounts the positive and negative effects on people. Look for negative longer term effects that build up over time. Look for unintended consequences.

Increase control of regulations by consumers. At least support the active involvement of consumer groups in negotiating regulations. This support may include helping people learn the skills they need to influence the regulatory process.

Time limit regulations to insure that they are renegotiated regularly.

Involve consumers and people close to them in reviewing draft regulations to ask exactly what they should expect from regulations and to identify possible problems. This purchases more thoughtfulness and improved foresight at the cost of making regulatory changes take longer.

Look for ways to regulate that support individualization and innovation.

Make tests of parallel systems such as peer review instead of regulatory compliance.

LIFESHARING AND OTHER PERSONAL COMMITMENTS

CONTRIBUTIONS

Answers the fundamental human need for committed, freely given relationships and for community of support and effort.

Complements each individual's gifts.

Raises basic questions--"Why are we here?"--for every member and provides the place for people to look for the answer with others who share the search.

Not necessarily dependent on human service funds.

Offers natural ways for people to meet and support one another without professional/client roles intervening.

LIMITS

Can't be done for masses of people.

Grows slowly in terms of the number of people included.

Relationships develop over time. There are lots of ups and downs. There are disappointments and sorrows as well as achievements and jobs. Lifesharing is not a "fix" for suffering, but a way to acknowledge and share suffering.

There are limits to what people can do for each other within relationships of equality and friendship.

Doing away with professional/client distinctions doesn't resolve issues of authority.

There are very powerful social forces against lifesharing. It contradicts many common beliefs and practices.

People do break personal commitments.

There are some people lifesharing doesn't suit.

Abuse is possible in lifesharing situations.

WHAT CONTRIBUTES TO EFFECTIVENESS?

More people to live voluntarily in intentional community, including people with positions in managing the service system.

Maintain the space lifesharing needs to grow by respecting its limits and not expecting it to take over for large numbers of people.

Avoid the temptation to present lifesharing as a fix.

Options for Action

by John O'Brien and Connie Lyle O'Brien

To Make Children Safer

More Powerful Families

→ We need to keep focus on strengthening and informing families with children with developmental disabilities. A child's parent or parents are the key to safety. Grandparents, aunts and uncles matter too. So do brothers and sisters.

→ When children live away from their families, it is important to make sure that families are welcomed, involved and listened to. If a child lives away from a family and has no family involvement, it's vital that that child have substitute family members.

Reduced Isolation

→ We need to work on ways to reduce family isolation and children' s isolation. Nondisabled school mates and university students have made such a big difference for some of our families. We need more ways to increase the chances that each child with a developmental disability will get a chance to meet "the other people" who can give the gifts of acceptance and participation.

→ We need to strengthen the sense of expectation that all children will be involved with their age peers in school and in recreation. Nondisabled children need to come to expect the presence of children with disabilities. This begins to overcome isolation and reduce the chances of abuse.

→ We need clearer, more detailed ideas about how to get the resources we all rely on to be involved with children with developmental disabilities without smothering them. We need good schooling without all containing special education; we need recreation without isolated special olympics.

More Effective Services

→ How do we encourage the development and employment of more teachers who have the desire, the ability, and the assignment to facilitate the development of relationships between disabled and nondisabled students?

→ We need to increase the range of alternatives available. People with disabilities are more vulnerable when they are uncooperative. They are more uncooperative when they are trapped in a situation that doesn't work for them. Most of the time there is only one situation possible. This increases the chances of a person getting trapped.

To Make Adults Safer

→ There needs to be clear avenues of recourse for people in every program, no matter what its type. We need to insure that someone who is in a dangerous situation has a way to let someone outside the setting know if there is a problem.

→ We have to work systematically on the essential issue: changing attitudes and expectations about the place of people with developmental disabilities in their lives, in our communities, and in society. This essential work begins with our own personal relationships with people with developmental disabilities and our own active involvement with our fellow citizens in the life of our own communities.

→ This kind of social change moves slowly, from person to person in social networks. This means keeping a long-term perspective on our policies and investments. People with developmental disabilities will be safer as more other citizens become personally involved with them.

→ We need to continue learning about what it takes to build and strengthen personal relationships and social involvements for those people with developmental disabilities who would otherwise be isolated.

- The best way to learn about this is through investments in local people's efforts.
- We should support a variety of efforts to be sure that communities have people who will be there to ask for and support personal involvements.
- As this body of evidence grows from projects focused on assisting people to become part of community life, we need to invest in communicating their lessons and sharing their tools.

→ We need to help systems explore more ways to put power, money, rule making, and monitoring in the hands of people with developmental disabilities and those people closest to them.

- The system we have now generates increasingly detailed rules within a system that institutionalizes major inequalities and disempowers people. We need to experiment with major changes in these systematic ways of keeping people unequal and without the resources to stand up for themselves.
- Just offering more of what we have now can't work to give the people the power they need to be safer. But demand on the system--from people who have little or no help now or from advocates for people who are especially and obviously hurt by the worst of current services--means big pressure for more. We need to focus influence and money on efforts to create windows for action to make the system different.

- There is much to learn about alternative ways to help people with developmental disabilities and the people closest to them to see, understand, and respond to the real risks in people's lives.

→ We need to face and explore the possibility that our social systems, including our service systems, are collapsing. Many people have not considered this possibility and some people who have think it unlikely. But a number of thoughtful people believe this is already happening, though they may not see the same causes or predict the same consequences. We need to find ways to assess this possibility (some would say, certainty) and help people explore the role of citizens in a collapsing situation.

Minimizing the Costs of Regulation

→ Understanding and achieving a balance of risk and safety is complex.

- Risk can come from strangers or outsiders, but it can also come from people you know and rely on such as service staff or family members. It would be easier to deal with this issue if all risk came from "outsiders" or if we could be confident that family and friends or professionals very seldom pose a significant risk.

- There is a theory that people are safer in community settings, which are more open, than in institutional settings, which are more closed. But what does "openness" mean? Does "openness" mean having lots of government inspectors visiting? How can a place be "open" and still be private? Does "openness" mean that a person has lots of friends visiting? If so, just locating people in small houses doesn't automatically mean they are in an open environment.

- Regulation can contribute to people's safety by insuring that sufficient authority is available to deal with bad situations. But regulation can make balance hard to achieve. It's very hard to develop regulations that are both powerful enough to rescue people from abuse and subtle enough to support people striving for balance.

- The idea of "the dignity of risk" is a valuable corrective to the tendency to overprotect and overregulate. But it doesn't provide much guidance for knowing when to choose for safety.

→ We need to do some hard thinking to place this issue in the context of larger social trends. Over the long term, demand on human service systems will continue to rise rapidly as other large scale social changes make strong demands for new ways to organize and manage. Formal systems will get more fragile and more erratic.

→ We need to ask what we can do to shape an environment that promotes the development of alternatives to widening the existing regulatory system.

STRATEGIES FOR INCREASING PEOPLE'S SAFETY

Work for social change...

* People with disabilities and their families are on the short end of social power. Remedying this means more than just increasing participation in service planning or service delivery. To get to the root of the problem we have to increase the political power and cultural standing of people with disabilities. Any response that simply focuses inside the service system will be incomplete, no matter how desirable it may otherwise be.

> "Any response that simply focuses inside the service system will be incomplete."

* The key theme is keeping people together. Disabled and able together in all life experiences from preschool on up, in work, in recreation, and in all of community life. Making this happen takes caring coaches for both able and disabled people.

* We need to make it clear that powerlessness equals abuse. That information, plus support from someone who cares, plus access to effective methods of recourse are the minimums necessary to safety for people with little power and control.

* Personal relationships are an essential part of any system to discover and act on abuse and neglect. People need others to confide in, others to see what's happening for them.

* We need to encourage everyone--starting with ourselves--to inventory our own abilities and disabilities so that we know what we all have to give and so we can start working on ways that each of us are weak in living well with other people.

* We are talking about increasing symbiosis among people. We need to talk more about humankind and less about people with disabilities as a "special" kind of human.

* We need to find more ways to link the interests of people with disabilities to other community members; for example, through the development of cooperative housing associations.

* We lack a technology for changing attitudes. And some of us think a formula can't ever be found for the kind of change that's needed. But we can set the stage for attitudes to change. We can be sure that people have role models of people with disabilities whose lives are successful.

Support the contribution of families & friends...

* Many people would be sunk without the support and advocacy of their family and friends.

* We have to think carefully and face some hard facts about family life and committed relationships.

- Lifestyles are changing. Many people have single parents. Many people have both parents working. Living well together takes time and having to advocate continually for necessities takes more time.

- There can be big differences within families in the extent to which a family member with a disability is valued and accepted as an equally valuable person by other family members.

- Many families and friends act apathetic--or numb--because even the services that are supposed to help are confusing and very hard to get what a person needs from. Information is hard to find.

- Not even getting listened to by people whose job is to help can burn you out on trying to ask for things from community members.

- Families and friends can be abusive and neglectful, especially when they lack support. We have a lot to learn about improving the ability of family and friends to cope.

- Some families and friends have very limited ideas about the possibilities for a person with a disability (so do many service workers).

- There is a great deal of talk about families disintegrating. We have to figure out what all this talk means. We can't afford to hope for something that can't happen; but we also can't afford to just pass around a lot of cliches about how bad everything is without checking them out.

* Vouchers for family support and (early) education services could increase access to integrated settings.

* Many families need opportunities to plan seriously about, "What happens when we no longer can provide what our disabled son or daughter needs?"

* We need to develop better ways to get information to families in ways that make sense.

* Families need to know from their child's earliest years how important it is for disabled and nondisabled children to learn with and from each other.

Support the contributions of service workers...

- Service workers (and regulators) need methods for "role release": ways to give up some control in favor of people with disabilities and their families.
- Service workers can gain in ability to "walk in people's shoes"; to look at decisions from the point of view of people with disabilities and to appreciate the life experiences that have influenced many people with disabilities.
- Service workers need to clarify and change their own possible contributions to disempowering people through everyday practices and routines.
- Service workers need to practice hearing what people with disabilities have to say.
- Building personal relationships between service workers, family members, and people with disabilities is important.
- It takes a lot of common sense to deal with people in a way that keeps them safe. Education and credentials don't necessarily mean empathy for people.
- Service workers need opportunities to reflect their work and their commitments to people with disabilities in small, soul-searching events.
- Service workers need to reflect on the kinds of educational experiences and back-ups that will help people with disabilities make good decisions in risky situations.

Work on service system issues...

- Lots of people need at least some help from services. But as people with disabilities represent increasing cash value to service providers and service system operators, the incentives grow to find things wrong with people and to keep people dependent. Under these conditions services necessarily must push people with disabilities away from community association. We need to find counterforces to this threat.
- Some people have nobody to count on except a busy case manager, who has too many people and too much paperwork.
    - These people need a buddy to advocate for them instead of having to wait for a case manager to get around to them.
    - Self-advocacy organizations can help if there are ways to meet and organize people who are alone and powerless.

- Case managers' jobs should be restructured. They should spend enough time to get to know people and check how things really are, not just short visits, or meetings, or looking at papers, but sharing experiences with people.

- If this restructuring of case management isn't possible, make it clear to everybody that the case manager is there for the system's paperwork and can't do much to keep people safe or improve things. Otherwise, people will think things are better than they are, and that's dangerous.

* High turnover among direct service staff makes it very hard for staff to know a person well enough to make good judgments about acceptable risks.

* The contradictions between how services are funded and regulated and people's sense of what is right creates a problem. The stronger staff commitment to positive rules and experiences for people, the more likely a conflict with rules and funding patterns. This increases staff frustration which could lead them to quit or withdraw from their work. We need to experiment with alternative ways to monitor and regulate services.

* It's important for writers and enforcers of regulations to see the real effects of their work on what we value in people's lives.

* We need to create windows of opportunity to maintain contact and respectful discussion between people concerned with administration, people concerned with advocacy, and people who are lifesharing. Our discussion shows that each way needs the other; each can contribute to mutual education. All must learn to focus on social and cultural change. It's easy to divide ourselves; we have to work at coming together.

TWELVE STEPS POLICYMAKERS CAN TAKE TO REDUCE REGULATORY EXCESS AND ENCOURAGE QUALITY

1. Treat different kinds of services differently; regulate agency-operated facilities, but permit flexibility for family-centered and person-centered supports.

2. Encourage phase-out plans for institutions and community-based facilities as an alternative to costly compliance plans.

3. Organize and support consumer, parent, and citizen monitoring communities AND act on their findings.

4. Specify rights and establish procedural safeguards for individuals with disabilities and families to challenge agency decisions.

5. Recognize quality services; highlight innovative agency practices.

6. Fund citizen advocacy programs.

7. Create funding mechanisms to enable adults with disabilities to rent or own their own homes.

8. Promote agency self-evaluations and external evaluations.

9. Provide funding to enable families or adults with disabilities to purchase services directly.

10. Disseminate information on innovative and promising practices.

11. Require agencies supporting people in their own homes to develop quality of life guidelines and plans as an alternative to certification.

12. Establish parent and consumer advisory committees and involve them in all aspects of decision making.

ADDITIONAL RESOURCES

Apolloni, T., Meucci, S., & Triest, G. (1981). *Monitoring the quality of life experienced in living arrangements: A guide to citizen participation.* Sacramento: California State Council on Developmental Disabilities, 1507 21st Street, Suite 320, Sacramento, CA 95816.

This paper provides a rationale as well as concrete suggestions for implementing a citizen monitoring system as a supplement to professional reviews.

Biklen S. K., & Moseley, C. R. (1988). "Are you retarded?" "No, I'm Catholic.": Qualitative methods in the study of people with severe handicaps. *Journal of The Association for Persons with Severe Handicaps, 13*(3), 155-162.

The article offers valuable guidelines for interviewing individuals with limited use of language.

Bradley, V. J., Ashbaugh, J. W., Harder, W. P., Stoddard, S., Shea, A., Allard, M.A., Mulkern, V., Spence, R. A., & Absalom, D. (1984). *Assessing and enhancing the quality of services: A guide for the human service field.* Cambridge, MA: Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

This report provides a valuable analysis of the philosophical and practical issues related to quality assurance followed by a framework for developing cost effective review systems that encourage innovative services.

Bradley, V. J., & Bersani, H. A. (Eds.) (1990). *Quality assurance for individuals with developmental disabilities: It's everybody's business.* Baltimore: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

In presenting the varying perspectives on quality assurance, including those of consumers and family members, the book provides direction in developing a more responsive system.

Mason, C. Y. (1990). *Consumer choice and satisfaction.* Washington, DC: National Association of Rehabilitation Facilities. P.O. Box 17675, Washington, DC 20041.

This is a report of a consumer survey conducted to measure the degree of choice and satisfaction in the lives of individuals receiving supported employment services. Included are examples of questions and techniques found to be effective.

McKnight, J. L. (1989). *First do no harm: A policy maker's guide to evaluating human services and their alternatives.* Evanston, IL: Center for Urban Affairs, Northwestern University, 2040 Sheridan Road, Evanston, IL 60208.

From a unique perspective, this paper shows the need and offers suggestions for evaluating the negative effects inherent in the structure of human service interventions.

O'Brien, J., O'Brien, C. L., & Schwartz, D. B. (Eds.). (1990). *What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities.* Decatur, GA: Responsive Systems Associates. (Available from: Center on Human Policy, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340. $2.95 plus $2.00 minimum shipping and handling)

Members of the Pennsylvania Developmental Disabilities Planning Council discuss the issue of how to strengthen community ties and improve services to increase the safety of individuals who require long term assistance.

Options in Community Living. (1987). *Options policy on quality of life.* Madison, WI: Options in Community Living, 22 North Second Street, Madison, WI 53704.

Options in Community Living, a support service agency for adults living in the community, prepared this policy statement to identify conditions that must exist to ensure a valued lifestyle in the community.

Patterson, J., & Associates. (1992). *Quality of life review & Quality enhancement process.* Tucson, AZ: Quality Associates, 3211 West Westwood Place, Tucson, AZ 85745

This is a workbook designed to guide team reviews of an individual's quality of life. Also included are strategies for enhancing the planning process.

ADDITIONAL RESOURCES (CONTINUED)

Schalock, R. L. (Ed.). (1990). *Quality of life: Perspectives and issues.* Washington, DC: American Association on Mental Retardation, 1719 Kalorama Road, NW, Washington, DC 20009.

Quality of life is examined here from a variety of critical perspectives, including conceptualization for the purpose of measurement.

Schwartz, D. B. (1992). *Creating a conceptual revolution in community and disability.* Boston: Brookline Books, P.O. Box 1046, Cambridge, MA 02238.

David Schwartz, Director of the Pennsylvania Developmental Disabilities Planning Council, reflects on the Pennsylvania experience. He discusses the dilemmas surrounding funding decisions and quality assurance issues that result.

Taylor, S. J. (1992). The paradox of regulations: A commentary. *Mental Retardation, 30*(3), 185-190.

This article reframes the relationships between regulations and quality of life. Though they sometimes act as a safeguard against institutional abuse, regulations are shown to undermine the potential for quality of life.

Wieck, C., Nelson, J., Reedstrom, C., Starr, J., & Stone, N. (1989). *Quality assurance resources: Instruments, organizations, and publications.* Arlington, TX: The Arc-US, P.O. Box 6109, Arlington, TX 76005

This book describes and provides ordering information for quality assurance instruments, organizations, and publications for monitoring services.

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