

Public and Personal Leadership Challenges

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This chapter discusses the leadership challenges that arise from reliance on the agency-based service system developed in the late twentieth century. It is written from the perspective of persons who use services standing at the center of leadership concerns. From this perspective emerge a number of fundamentals to guide the commitment of those in leadership roles on behalf of persons in the client role. While this chapter does outline several great challenges, it places them in the broader context of societal and personal change. Thus, systems change is itself dependent on more profound changes in who we are and how we live.

LEADERSHIP CHALLENGES IN SYSTEMS CHANGE

Leadership is central to any process of change, whether the leadership arises out of individual charisma; preexisting agreement on leadership because of common values, goals, and interests; or the urgency of necessity. Often the existing resources that potential leaders could utilize will go unutilized because the focus that leadership can bring to a situation is lacking. Leaders must always be concerned with the question of how to make use of resources available in the situations they face. Otherwise, the potential of a situation may not be mobilized.

Leadership must be judged not as a factor outside of the flow of history, but as a factor of deliberate human agency within history that causes events to take a particular direction. The challenges facing leadership are rarely those preferred by leaders; rather, they are usually obstacles, opportunities, and hardships determined by prior events. These inherited circumstances contain intrinsic challenges that the potential leaders choose whether or not to address. The worthiness of leadership is judged against the emerging issues of the situation. Naturally, all judgments of this kind arise out of pre-existing beliefs and assumptions about what leaders should address.

THE RISE OF COMMUNITY SERVICE SYSTEMS

In the field of disability and in other fields in the United States a noticeably massive configuration has arisen since the 1970s called community services. A comparable process has occurred almost simultaneously in many countries in often strikingly similar ways. These community services are quite varied and in many localities are arranged as systems of services that aspire to be comprehensive; that is, they seek to address all of the life needs of particular subgroups of persons with disabilities. To call these arrangements systems, however, may assign a greater rationality and relevance to them than they can live up to. The reality is often that systems grow helter-skelter in an incremental manner, the net accretion being described as the system.

What is remarkable about such systems is that largely they are novel and unprecedented. Never have people had to rely on anything quite like community service systems to address the life needs of persons with disabilities. Because this system of services has become the norm, society forgets that it is peculiar to the late twentieth century. There has not been much long-

range experience in managing such complex systems. Still many in the disability field now see community service systems as a massive part of public life, so that it seems impossible that any leadership would not encounter the problems posed by such systems at some point, even if these systems are variously abandoned, demolished, replaced, or reconstituted.

In large part, the growth of such services has been intertwined with the transfer of social responsibility for services to the state. The growth of such services and systems has been fueled (and limited) predominantly not by charitable sources, as was formally the case, but by governments increasing their taxes to support various versions of the welfare system. This has created entitlements to assistance that heretofore either had not existed or had been left as the ambiguous prerogative of families and other concerned persons. In the name of abstract public personal assistance, the government was expected to undertake responsibilities greater than what most strangers might normally do for other strangers. In many cases this level of responsibility might well exceed what is expected of a devoted but imperfect family in caring for its members.

The sheer scale of such activity and responsibility has meant not only a vast increase in public expenditures, but also a compelling increase in the scale and dominance of the mechanisms of administration of the resources. The service bureaucracies have expanded both directly by adding personnel and responsibilities to public agencies, and indirectly by contracting with pseudo private agencies. These private agencies typically are dependent on the state and, thus, are seen more realistically as extensions of the state rather than expressions of a pre-existing independent private interest. In all likelihood their growth and standing has arisen from capturing public expenditures and legitimacy rather than from private interests that would have prevailed irrespective of what the state did. Their growth, character, and identity have been shaped massively by the character of governments.

THE CHARACTER OF AGENCY-BASED SERVICES

Out of the wide range of ways which societies have chosen to assist their members throughout history, the method used at present is distinctive. Broadly speaking, the pattern of service is agency-based, that is, it relies on creating agencies to act on people's behalf when they are unable to or unlikely to act on their own. The mediator of this process of services is largely the state, which causes the service system to be characterized as a public, collective, politicized, and abstract undertaking.

Since the essential context for services typically is a public agency (notwithstanding its superficial trappings as a private effort), it is noteworthy that, almost by definition, it is impossible for a service not to involve formality in its exercise. Whether such formality arises out of, for example, contract obligations, eligibility, or formal legal requirements, it is structurally impossible for services to be informal or to arise out of the unmediated interactions of individuals. In a symbolic sense, the government is present as a silent participant in each interaction, even if the participants are informal in their conduct. In this way a formal, independent relationship exists that neither participant can be free of by assuming a relaxed manner.

Furthermore, regarding informality of assistance, currently, much talk is heard of natural supports. This approach to assistance is often problematic because "natural" in this sense usually means something unmediated by or not dependent on service bureaucracies. Service bureaucracies are not unnatural nor are informal services rendered by one person to another on a

private basis natural. Both are creations of culture and can be seen logically as intertwined with a larger social system. Whether that which is characterized as natural is more efficacious, moral, or otherwise superior cannot be determined simply by its tie to, or its distance from, a service bureaucracy, unless one simplistically equates agencies with malevolent purposes.

Additionally, virtually all agencies, in one manner or another, are bureaucratized. While advantages may accrue from bureaucratic organization, few would deny that bureaucracies contain powerful obstacles to functioning. Common bureaucratic dysfunctions include goal displacement, poor coordination of effort. Learned irrationality, rules fixation, turf wars, and inefficiency.

Added to these dysfunctions is the fact that employees of bureaucracies are normally strangers who are not encouraged to deliver personalized service. While such arrangements of paid service are not unheard of throughout history, the scale of service being undertaken in this impersonal and commercial manner is unprecedented now. Put another way, the client of services is now utterly dependent on a whole complex of strangers for their assistance. Many people appear to favor this impersonality because of the perceived drawbacks of obtaining assistance from family members or other familiar people with whom they already have an intimate and perhaps problematic relationship. Similarly, many believe that social distance ensures objectivity. Objectivity in this sense usually means accurate, fair, and not in conflict with other interests and needs.

Intertwined with service bureaucracy is the related phenomenon of professionalization. Service bureaucracies are inhabited by classes of workers whose work identity exists only in roles in such systems. Were it not for these agencies many professions would not have an ecological niche. For example, an employment specialist could not exist without supported employment services, and a service coordinator could not exist without disparate services to coordinate. While the differentiation and rationalization of tasks is classically associated with bureaucracies, this does not mean that professionalization per se is a synonym for usefulness, efficiency, or relevance. Equally, professionalization is always mediated by interests that are at variance with the general public good as well as the good of those cast in the role of consumer.

Service agencies frequently are hierarchical not only in the administrative sense, but also in the sense that organization of power and of control is such that the consumer typically is at a disadvantage. This may be expressed further in the absence of mechanisms with which the consumer, his or her friends and allies, and the broader public can direct what assistance they receive. Agencies may create participatory mechanisms to compensate, but this does not change the common reality that the agency is dominated by its own internal hierarchies and seeks advice at its own discretion. Under such conditions, strong community control and direction and commensurate empowerment become very unlikely unless they are deliberately pursued.

As the state has expanded into the role of service provider, it has generated a simultaneous increase in the number of agencies and their size. Increased size alone has led agencies to become more complex, exert more control, consume more public resources, become more distant from the consumer and local communities, and become increasingly bureaucratized. While the absolute growth of public expenditures to feed such aggrandizement will eventually reach some limit, the vast majority of agencies have not deliberately restrained their own growth, and many run as if this expansion poses no dangers. While this may be due in part to naiveté, it is striking that predictable tendencies toward, for example, empire building are so rarely discussed as factors in agency aggrandizement.

Community services sometimes are so large-scale that they are incomprehensible to average citizens. This may be so not only because professionals encourage mystification of service activities, functions, and interests, but also because large-scale alone renders service agencies difficult to comprehend, monitor, shape, and rehabilitate in the community interest. Curiously, some community agencies serve so many people that the consumers are literally anonymous and even innumerable. This is compounded by the presence of large "community" agencies operating in many communities including, more and more, communities literally on the other side of the continent. It is reasonable to question whether the word community should be used to describe services on a scale too large for them to be ultimately molded by local communities to fit local needs. Localization of service, decentralization, and superficial participatory structures do not change the reality that the local community has increasingly become merely the site for an outlet of a mega-agency. The character of such agencies is now effectively expanded beyond local direction as opposed to arising out of it. Thus, characterizing large-scale services as community services is an incorrect portrayal of who actually owns the services.

TRUST IN THE COMMUNITY AS A CORNERSTONE OF COMMUNITY SERVICES

While there has generally been a wholesale expansion of public services since the 1950s, the rationalization for this meta-process in the field of disability has drawn heavily on ideology that emphasizes community contexts. Expansion has taken the form of deinstitutionalization, as well as greater inclusion of people with disabilities in the clientele of community resources. Such broad ideological goals make for diverse interpretations for specific community hopes and expectations, ranging from near utopian expectations of rapid social inclusion to continued existence in punitive segregation.

Just as in the reality of services, there are many realities of community life for all citizens that are problematic. While it is true that institutions are rife with disadvantages, the presumption that community life does not have its own problems is invalid. Furthermore, institutional problems are reincarnated in somewhat modified forms in everyday community life. Therefore, the community may not be the fulfilling context that is hoped for. For instance, community living may routinely subject people with disabilities to continued social devaluation, rejection, exploitation, disregard and neglect, abuse, segregation, abandonment, poverty, powerlessness, and so forth. It is noteworthy that so many advocates of community living seem incapable of being truthful about these predictable constancies in the human condition.

Many reformers seem to believe in a community free of this neglect and oppression. This view of community can have an unromantic basis because there are massively important and positive ways in which people can be perceived and included in community life. However, this enriched view of community does not take into account the situation in which people with disabilities are present in the community but have social roles that devalue and degrade them. This situation, in turn, brings up the question of what elements of life in the community to emphasize in order to ensure persons with disabilities a quality of life at least commensurate with that available to other citizens.

LEADERSHIP CHALLENGES POSED BY AGENCY-CENTERED SERVICES AND COMMUNITY LIVING

The term system commonly is used in referring to an organization but can refer to any pattern or order. For example, the term system is used in ecology to depict the logical interdependence among elements of the environment and the life forms that it sustains. Regarding services, the broad context of the cultural order of which services are a part could be referred to as a system. Leadership is addressed here in the context of the character of the broader social system rather than simply as a problem of managing services.

THE PROBLEM OF SOCIAL DEVALUATION

The cultural order that has produced agency-centered service systems has dealt only in part with the fact that, historically, it filled its residential institutions with largely unwanted people whom it collectively devalued. Those not in institutions were scarcely more socially valued, though, typically, they were far less dispossessed and debased. Inclusive ideologies and community services have been only partially effective against this social devaluation. The system of services as well as a disembodied ideology of empowering inclusion may well obscure and accommodate to a deeper and continuing ambivalence toward persons with disabilities. Broad compliance with legal and other imperatives for inclusion has not brought about deep social acceptance.

A closer look at communities reveals that most people with disabilities are not viewed as equal members of the human race. This is manifest every time these individuals' wants, needs, and entitlements are assumed to be less than those recognized for others. The test of true social valuation has to do with whether the social valuation of a group is comparable to that of people in the general culture.

This test partly concerns whether sufficient leadership and leadership interest exists in creating the true heart of community as opposed to more superficial and unconvincing expressions of tolerance. Leadership toward a community with true heart is necessary to bring about community life in which people with disabilities are not automatically thought of as tragic, pitiful, burdensome, or unattractive. In communities with this kind of leadership perhaps prospective parents would choose not to abort their children with disabilities. Similarly, public gatherings without people who have disabilities would seem odd.

These examples are among the values that society must affirm to ensure relative security for people with disabilities in community life. Affirming positive values involves exposing false values. Effective leadership is needed in both cases. This leadership will emphasize repeatedly the identity and needs of people with disabilities. A moral relationship between ideological leaders and people with disabilities is presumed here. Leaders involved in this relationship include people with disabilities themselves, families, advocates, dissident professionals, visionary politicians, journalists, artists, and others acting either individually or collectively in challenging society at the level of its values.

CREATING AND SUSTAINING VALUED SOCIAL ROLES

Successful values leadership involves more than adopting pleasing slogans. Real change establishes and enhances valued social roles for people with disabilities in community life. This goal is not a service goal; rather, it is a broader attribute culture and social relations. Furthermore, it is utterly entwined with the internalization of authentic values change and its expression in the conduct of ordinary people.

Valued social roles will be established and enhanced through generations of effort. This long-term effort calls for a sustained effort at leadership by many ordinary people acting out of their specific circumstances. Consequently, prospective leaders should focus attention on circumstances of everyday life in which people with disabilities are forced into devalued social roles or are taking positive, valued roles. These circumstances are flashpoints for moments of decision on personal action and, more broadly, resulting collective behavior. In this way everyday life is a litmus test of values authenticity.

ORDINARY CITIZENS AND EVERYDAY RESPONSIBILITY FOR SOCIAL INCLUSION AND SUPPORT

As discussed above, the presence of impersonal services indicates that citizens have failed to be responsible for each other. However, social acceptance, inclusion and the accordance of personal worth do not primarily come through agencies. Rather, these qualities of life require the will and commitment of ordinary people. When these qualities become the norm, then a commensurate change in social pattern will occur. The leadership challenge is to mobilize people to comprehend and consider this prospect and eventually decide where they can make a contribution.

As people's responsibility to each other has been supplanted by agencies, people without disabilities have been encouraged, thereby, not to concern themselves with the lives of individuals with disabilities. Changing this situation means no longer embracing agency-centered services as a social remedy. Rather, people should be encouraged toward personal responsibility to one another within the range of appropriate personal obligation. People with disabilities have needs relevant to work, income, family, security, accomplishment, growth, and so forth, which are the same needs other people have. Addressing these needs can be accomplished in normative ways. Leaders have the task of initiating and encouraging the change in consciousness needed to bring about this type of commitment people and resources.

Encouraging individuals without disabilities to reconsider their relationship with people who have disabilities speaks to peoples characters. The process of relationship involves people's positive and negative traits. Thus, there will always be situations of partial, incomplete, or ill-advised inclusion. Consequently, critique, challenge, and guidance are needed to keep values and actions in check.

Ordinary people taking responsibility for one another could be construed as an alternative to agency-centered services. This alternative is workable for some people, but the practical means for taking the full extent of responsibility for all people with disabilities will not be available to other individuals. The huge investment of social resources in agency-centered services prohibits this availability. These same resources would have to be reinvested in supporting the ability of ordinary people to assist each other. As it stands, small, citizen-based and citizen-directed measures have little funding because agency-centered services receive so much.

However, this proposed reinvestment of resources would only curtail agency-centered services. Though professional and agency activities could be undertaken as community efforts, communities may prefer not to become involved, thereby creating a role for an agency. Furthermore, the practical competence of many professionals and agencies exceeds that of unsupported, disorganized, and inexperienced citizens. Finally, even if some people do not devalue people with disabilities, the fact that others do impedes the ethos needed for people to be responsible for each other.

LISTENING TO THE CONCERNS OF PEOPLE WITH DISABILITIES

People who have disabilities and all people who experience social devaluation usually are not taken seriously when they complain or suggest improvement. While paternalistic approaches in the field may bring about improvement, change is limited if it does not consider the will, insights, and aspirations of people with disabilities. Understanding that people with disabilities are entitled to self-determination does not mean viewing this or any other socially devalued group as infallible, superior, and unchallengeable because they have lived under oppression.

The sounder attitude is that people with disabilities must be accorded the common dignity of self-determination to the extent that most other people are. The leadership challenge is more than to promote self-advocacy groups; it is to promote an attitude of basic regard that includes the needs and preferences of people with disabilities with the priorities that shape the culture. Thus, as people do speak for themselves, leaders are needed to encourage others to listen. In a curious way, good listening is proactive self-advocacy. If people are heard and understood as a matter of course, they do not need to speak up in a deliberate sense. Being heard protects, for example, equal educational opportunity, universal access, freedom from stereotyping, and the lives of people unwanted because they have disabilities. Leadership is essential to building these qualities of life into the fabric of community.

THE CONTRIBUTIONS OF PEOPLE WITH DISABILITIES

Perhaps one of the most perverse roles society puts people in is that of "client," in which they are perceived entirely as receiving the charity of society rather than contributing to the virtue and richness of society. People with disabilities, like many other groups of people cast as "needy," are given the function of providing those who assist them with what could be construed as a reason to congratulate themselves. Whether some of the assistance given is at all useful may be arguable. Still, those who provide it reward themselves with self-congratulation and other psychic rewards.

This condescension negates the intrinsic value of people with disabilities and precludes their opportunity to contribute to society. Thus, any constructive leadership strategy must grapple with the problem of society's perception of people with disabilities because it presumes that they cannot, and are unwilling to, contribute. In reality, people with disabilities can make contributions as varied as anyone else's. While the actual contribution is important, society's underlying perception of ability and willingness to contribute is even more important.

SERVICES THAT TRULY ADDRESS THE NEEDS OF THE PEOPLE USING THEM

It is not entirely clear that services can be free of certain struggles in addressing people's needs appropriately; people are imperfect and so are the systems they create. Still, creating favorable conditions for providing appropriate services can be accomplished. However, being able to create these conditions is by no means assured by agency-centered or professionalized services or by resorting to informal, natural supports only.

The process of service emerges out of interests, limitations, intents, capacities, and values that routinely may be incompatible. Agency-centered services are invariably suffused with competing interests, which often causes the practicalities of serving consumer interests to be subverted by the practicalities of serving other interests. When this happens, the service provider comes to view the interests of the consumer as a low priority. Informal supports also may sacrifice the interests of the individual supported when varying interests exist. In families this may mean that the interests of other family members are given priority over those of the family member whose interests are least convenient to attend to.

While the concept of interests or needs is understandably complicated, it is clear that services often fail to provide what the individual truly needs. The service provided may be irrelevant to the individual's actual needs or relevant but not addressing needs that are basic to the individual. For example, discounted telephone service would be of no use to someone who is homeless. The more fundamental need to be addressed for this person would be the need for a residence.

Society invests extensive resources in services, so its failure to address needs appropriately should cause great public concern. This failure to address needs appropriately can waste resources by forcing useless services on people and even harm people by forcing them to use services that are damaging. Wasted resources are unavailable for valid uses. Effective leadership can help keep service delivery on track. Leaders are faced with the challenges of both keeping services as relevant as possible and detecting, critiquing, and eliminating irrelevant or inadequate services.

SAFEGUARDS AGAINST SERVICE DYSFUNCTION AND FAILURE

There will always be ideologies, mythologies, and interests that portray services as incapable of breaking down or otherwise failing those in the role of client. Some ideologies are rooted in the belief in a level of human conduct (on the part of individuals or collectives) that precludes decadence, error, perversity, dysfunctionality, and ineptness. For example, many organizational specialists seem to perceive all human conduct as able to be socially engineered. An engineering analogue applied to human behavior can be deceptive.

While some services may not be dysfunctional or harmful either in principle or in day-to-day reality, it is quite another matter to suggest that services are incapable of harming those they are intended to serve. With the lives of vast numbers of human services clients now massively bound up in the system of agency-centered services, it would be irresponsible for leaders not to ponder the disturbing issue of service dysfunction and failure and how to prevent or correct it. This is essential, especially when few clients can now do without formal services.

There is a history of people with disabilities being abused and neglected in institutions and by the community. It is crucial that safeguards be built into services to ensure protection for individuals being served. Making the effort to learn from history maintains a conscious link to the continuing reality of human nature. Far from precluding abuses and failures, this link points out the possibility of their existence and highlights their actual existence.

CONTROL OF SERVICES LYING WITH THE INDIVIDUALS SERVED

As indicated earlier, truly respecting the dignity and autonomy of those using services entails listening when they voice their needs. There is something unalterably profound and equalizing in giving due respect to the voice and humanity of people whose identity is unrelentingly devalued in everyday life. Those battling stigma, neglect, impoverishment, powerlessness, and dehumanization are further harmed by services intended to help that ultimately dis-empower them--- obviously or subtly. Furthermore, the rhetoric of person-centered services may substantially obscure the actual dis-empowering effect of services.

In order for those who use services to have more control over them, a great deal of change in the values, structure, and alignment of interests of service systems will be required. Many attempts to give more control over services to the individuals who use them fail because they do not make these changes. The solution, therefore, is not found in restructured service measures alone but necessitates fundamental societal realignment of ideology, power, and interests. This includes the realignment of control of services in such a way that those served can shape the character of services. This logic is not predicated on the assumption that consumers always know best; rather, the assumption is that services must be coherent, understandable, and relevant to them. Furthermore, services are more likely to have these qualities if they are designed based on the experience and priorities of those who use them, rather than these individuals being relegated to the position of being put upon by professional judgments. The process of breaking up the exclusive control over services that is held by human services managers will entail changing vested interests, practice, and structures through fundamental changes in belief and attitude about the capabilities of people on either side of formal services. Human beings have great difficulty changing on a fundamental level, so leaders will have great difficulty stimulating service personnel in these more progressive directions.

REDUCING BUREAUCRACY IN SERVICES

The notion that people can help each other only through the mediating influences of service bureaucracies is dominant currently. Therefore, more informal ways of helping each other sometimes are not even comprehended by those accustomed to bureaucracy. It falls to leaders to discover effective forms of assistance that are non-bureaucratic.

Not all alternatives to bureaucracies replace them effectively. For example, individual funding schemes may provide for those who use assistance to have greater influence on it, but these schemes are still embedded in a bureaucratic service system. Also, group homes typically are more embedded in a bureaucratic service system than adoptive homes, which function for the most part outside of service bureaucracies and in a manner that is more culturally normative. Similarly, a situation in which an individual uses a special needs allowance attached to his or her fixed income to hire neighbors for personal assistance is far less bureaucracy than assistance from neighbors being enlisted by community agencies. Neither is entirely separate from service bureaucracies, but the former provides assistance much more naturally.

Effective alternatives to service bureaucracies will not always be clear. Leaders face the challenge of pressing for those alternatives that free society from the disadvantages of making service delivery through bureaucracy a necessity. Even where there are elements of service bureaucracies that have some effectiveness, it is still useful to probe whether this same effectiveness could be obtained without the drawbacks of bureaucracy.

THE SPIRIT OF SERVICES

Services are usually embedded in agencies, but they are delivered by human beings. The human character of providing services encompasses some quality of spirit in terms of regard for the worth and dignity of those using services. Inevitably, this spirit will dominate the relations between those using services and those delivering them. It is essential that this spirit be genuine and positive for services to address people's actual needs.

Leaders can have their effect at fundamental levels. They can inspire service providers to deliver services in a manner that is encouraging, but they can also have a negative influence. Negative service situations do not necessarily result from absence of leadership. The leadership may be competent but lacking a positive spirit. One of the ways in which this positive spirit may take form is through legitimation of the issue of recognizing the intrinsic value of the lives of people using services and actually listening when they express their needs and concerns.

SUMMARY

In these times of reverence for science and its assorted technologies, there is often an attempt to reduce problem-solving to a formula. Leadership through a strategy of mechanical oversimplification poses great risk. The leadership challenges presented here are intimately tied to questions on deeper levels. Quick fixes and minimizing leadership issues into superficiality are unlikely to produce enduring, relevant leadership. Leadership challenges call for attention on all levels.

Ultimately, organizational and conceptual tinkering will not alter much without changes in the way people think. With this type of change comes leadership that is not so much altruism as a reflection of a connection to the deeper currents of the psyche of prominent people and ordinary people alike. The issues identified in this chapter are both greatly public and intensely private. Therefore, addressing these issues is a challenge to public life as well as personal life. Fortunately, this broad continuum of consequences permits many people to rise to the challenges as their positions allow.

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