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SOME OBSERVATIONS ON KEY LEADERSHIP CHALLENGES IN THE FIELD OF DISABILITY: A COMMENTARY By Michael J. Kendrick PhD (1999)

The idea of leadership lends itself to any number of applications and it is useful to try to be more precise as to what meaning of it is being used in a given instance. The sense of leadership that we will begin with here relates to the crucial task of providing purpose and direction that is commonly used in most of the more widespread definitions of leadership. This phenomena of leadership can be thought of as arising both from the actions of individual persons and from the collective effects of their efforts when combined with those of others. Whether this effect is intended or not or whether it is consciously coordinated may not, in itself, preempt the possibility of it constituting leadership since the cumulative results of many actions may have results that differ from the intentions of specific persons.

The disability field is much more than the professions that work in it and the organizations that define much of its activities. It is composed of all sorts of constituencies and interests of varying strengths and influence. These might include the many different sorts of people who live with diverse disabilities, their families, friends and social networks, the many people who work in one capacity or another in the formal services which populate the field, the many governments, regulators and administrators which oversee the field, the educators, consultants, researchers and academics which focus on the field and many others including the various “publics” that interact with the field.

The “field” might best be thought of as something more akin to a social movement in that it draws part of its vitality from the numerous constituents acting together though not necessarily through the same bodies. This “acting together” suggests a kind of coordination that may not in reality exist since so much action is coalesced through common purposes and frameworks rather than through deliberative authorities or coordinative bodies. What coordinates a social movement are shared frameworks of values and ideologies that serve to unite what otherwise would be unrelated personal actions. Thus it is hard to imagine a proper understanding of leadership that does not take into account what it is that moves people to act and gives such action direction and purpose.

The concept of a “leadership challenge” refers to key tasks facing leaders or that leaders ought to or need to take up. It generally implies that such challenges are crucial to the interests or well being of the domain under consideration. In the case of the disability field this would mean issues that constitute “core” or fundamental matters that go to the heart of the field and its concerns. What are selected here for discussion and examination are several of the challenges that leaders must address in the coming years if the field is to advance. There is no necessity that such advances occur as progress is not a “given” as it depends on whether there are present the kinds of people who might have the capacity to seek such gains.

Crucial amongst these will be leaders, as they are the people who will be the catalytic force that ekes whatever opportunities can be created or pursued. “Leaders” do not necessarily mean persons who occupy formal roles of leadership, as many such persons may not actually be providing leadership. Leadership can readily be expected from any number of people who lack formal authority, but who nonetheless have a great deal of influence on the purposes and direction of events. In this sense, leadership in a social movement can often be informal and outside the “official” structures of authority and decision-making. In the case of the field of disability, one frequently sees leadership being offered by any number of people whose involvement in the field is not through formal roles but rather through the issues they try to address. This has included citizen activists, families, people with disabilities, employers, neighbors and others.

A) Establishing Shared Vision, Values and Purposes

It is important to recognize that the character of all human conduct is premised on values, whether these are particularly conscious to the person or not. Interlinked to these guiding values are ideologies that contain the key assumptions and theories that help shape how the world is organized and defined in the perceptions of the adherent. It is not possible for humans to live in a world without definition and thus how meaning is made of and in the world is central to the behaviors that effuse from people. Leadership is inevitably part and parcel of the process of bringing about shared agreement amongst collectivities of people as to what they will care about and commit themselves too.

In the case of the field of disability there has been and will always be incessant challenges to the priorities of what will dominate the focus and best energies of the field. These might come from both outside and inside the field as conditions unfold, but it will invariably be the task of leadership to resolve what are to be the matters that will be considered important. Leaders do not, of course, in themselves, solely determine the outcome, but they typically participate in influencing people as to the content of these eventual value decisions. Leaders are therefore both constrained and authorized by the consensus that exists as to values. Whether their ultimate purposes are realized will be highly contingent on whether their values are found to be persuasive to sufficient numbers to generate an enabling consensus, given the aspect of the field that they operate in.

It is a necessity of social existence that people see many things the same way if they are to cooperate and advance together. Where a common vision exists, it acts to enable people to unify their efforts around a shared sense of what is possible and desirable. Leaders play a necessary role in building such a vision, both by offering unifying themes and bridging the visions of many into overarching ones. This eventually results in constituencies that authorize action and thereby enable vision to become translated into practice. It is not necessary that leaders be the authors of vision, though that can occur. More typically, leaders embrace and uphold a vision as integral to their claims of leadership. Leaders who lack vision will, of course, find it very difficult to make progress, as they have no direction in which to proceed.

If the vision of leaders is not embedded in the actual life experience and needs of persons with disabilities, it is quite conceivable that the directions such leaders may pursue could be mistaken, even if well motivated. This sets up a test of the leader as to whether they are going to be advocates of visions for the potentialities in the lives of persons with disabilities that are positive and relevant. Not all visions are sound, even if they are well intended, widely supported and ably led. The quality of the vision must ultimately rest in the real results that flow into the lives of people and whether these “fruits” or legacies of leaders are uplifting or degrading to the vital life interests of people with disabilities. The challenge for leaders is therefore, not only to be part of creating vision, but also asking what is the vision that is most needed and will bring about the most enduring good. This struggle with the moral and values content of vision to ensure that the vision proves to be ultimately beneficial, is a critical task and certainly one that distinguishes leaders who matter, versus ones that do not challenge us to be and do the right thing.

It is quite clear that leaders exist who are very competent in achieving support for their aims and ambitions. These persons are undoubtedly talented performers from the point of view of their proficiency and their ability to prevail. Nevertheless, the question of the suitability of their leadership cannot solely rest on their technical persuasive prowess. This is because the full effect of their actions as a leader cannot be separated from the content of the values and directions they endorse and the real world human consequences that result in the lives of people with disabilities.

As has been witnessed in the past, leaders may serve purposes that ultimately prove to be morally unacceptable, even if for a time they have found support to proceed. It is important to recognize that leadership is still ultimately bound by norms of moral acceptability, even though politically they may have temporarily achieved the mandate to act. The example of the Nazi genocide against disabled persons comes to mind, as does the related case of the twentieth century eugenics alarm period that resulted in the unjustified forced sterilization of so many people with disabilities. At the time of the enactment of these policies there was certainly little enough opposition from the field, thereby permitting the unchallenged implementation of these crimes.

A key moral and values question that the field must continually deal with is that of whether the field is acting in the best interests of persons with disabilities or whether it has compromised such interests. This is partially a question for the broader society, but it also has internal–to-the-field dimensions particularly in regards to those matters that are done as a matter of public trust. Even advocacy groups must ultimately answer for their stance or lack of it in the face of the values challenges that exist at the time of their existence. A good example of this would be the position the field takes as to whether persons with disabilities should receive fair treatment in their society or whether they disproportionately end up being harmed. The current persistently negative statistics on the level of reported abuse of persons with disabilities within community life represents one such instance. If the field has faithfully dealt with this matter in its role as a trusted agent of the public interest then it must assure that people with disabilities are treated conscionably. A failure of leadership would occur if the field ignores or fails to take up this challenge, thereby leaving people with disabilities to their fate.

This broad leadership challenge of supporting values that act in the best interests of persons with disabilities falls into three broad domains. The first is that of identifying and promoting values and ideas that are crucial to the overall well-being of persons with disabilities. A good example of this has been the lengthy campaign that is still underway for people with disabilities to be a greater part of family and community life as opposed to living lives of exclusion and segregation. The fact that this goal is still unrealized is not “per se” a failure of leadership, since its achievement must be balanced by a recognition of the inherent difficulties in achieving deep levels of social integration where there had previously been very little. The very fact that society has to be continually challenged to make this goal more real is, in its own way, a sign of the seriousness with which the public trust to advance the interests of persons with disabilities is taken. It means creating pressure for what is possible, desirable and feasible, even at the cost of challenging the public's own customs.

The second task is to identify and challenge values present in the public domain that pose a threat to the well being of persons with disabilities. In some ways this is the inverse of the proactive function in regards to positive values, in that it requires a conscious engagement of the attitudes, beliefs, theories and interests that could contribute to the harm of persons with disabilities. A good example of this is the well known work of many people in the field to ensure that a legal status not be created for persons with disabilities that would permit them to be treated as having less rights than their fellow citizens. This can be seen in the practices wherein people with disabilities had been arbitrarily denied customary rights such as the right to consent, freedom to not be unlawfully confined, the right to vote and so on.

The third task is to strengthen the engagement of people with values questions themselves. The lack of the thoughtful examination of matters of value can often lead to unwise courses of action, even in situations where the values themselves are not principally at issue. It is often the interpretation of values that is problematic, as it is quite possible to do harm by the way one operationalizes the values. This can be seen in the example of well-intentioned people unwittingly depriving people of their autonomy in the name of safeguarding them against otherwise properly recognized sources of harm. Such overcontrol begs the question of clarifying other values pertinent to sensible safeguarding practice, such as the necessity to not make personal security the only or primary consideration in safeguarding the life circumstances of people.

The need for shared purposes and values is evident if the positive values are to be settled on in the collective as well as personal sense. The lack of agreement on shared values will serve to inhibit unified action, exacerbate divisions and the consequences of these, and provide fuel for incoherent approaches to problems. On the other hand where there is agreement on key assumptions, premises and values the likelihood of making progress on many crucial matters improves. Leaders that presume that key values issues have already been resolved may often find that this is not so, particularly as these are tested by events. Thus, the task of ensuring that values related issues get sorted out is a crucial component of ensuring that positive directions eventually come to be realized. The process implications of doing this well are not to be underestimated, given the inevitable differences within the underlying values that pervade public life.

The overarching vision that has held the field together until quite recently has been the hope for people with disabilities to eventually gain access to the full potential benefits of community living. Much progress has been made in this regard, particularly as it has related to getting people out of segregated settings as institutions, nursing homes and sheltered workshops into better ones. Even so, the dubious quality of many of the current options in community life for people with disabilities has raised varieties of questions about what constitutes better or worse forms of community life. This question further raises the challenge for leaders to position the field to move past the formerly unifying theme of the goal of community living to the now more important matter of the actual quality of that which is called "community living". Not all that happens in communities is praiseworthy, nor should it be tolerated simply because it nominally happens in otherwise normative community contexts

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Such a newly refined vision, while helpful for updating the relevance of the field's agenda, is also likely to be divisive to the extent that it questions interests and practices that are presently quite orthodox. Yet much of what happens in conventional community services ought to be questioned if it serves to act against the best interests of people with disabilities. This ambiguous task of leaders to both challenge and unify the field sufficient to make progress is unavoidably conflictual, simply because the introduction of useful changes inevitably will disturb whatever had preceded it. The task of leaders is to help people see the issues and their importance, to come to decision on addressing the issues correctly and gaining consensus to act. Such a process will need to be repeated many times if the quality of community living is to improve.

B) Strengthening The Voice and Influence of Persons With Disabilities

It is now quite common to hear claims of many kinds related to the advancement of the empowerment of persons with disabilities. These often take the form of admonishments towards an increased recognition of the need of persons with disabilities to experience a greater degree of self-determination on most matters of importance in their lives. Insofar as this goes, such sentiments are very much overdue given the paltry amount of influence that persons with disabilities actually experience in most matters. This latter recognition nevertheless does raise serious questions as to what would constitute an adequate response from leaders to such a set of circumstances.

It is readily apparent that many people with disabilities are strikingly limited by assumptions people may have about their disability in their capacities to gain and exercise worldly power as well as their own. One can see this most readily in the life circumstances of persons with substantial mental and physical limitations. Inevitably, such persons will be at substantial risk of being dominated by others unless there are factors present that neutralize the inherent advantages that lay with people who are more able than they could ever hope to be given our negligible current ability to reverse disabilities of this kind. It is certainly true that persons who are less impaired could well play a larger role in gaining personal influence and power in many situations in their lives. Nevertheless, nothing is to be gained by denying the vulnerability that may be inherent in living with a disability relative to the comparative advantages enjoyed by people who do not have to face the limiting effects of a disability, particularly at the level of pereptions and assumptions about the capacities of persons with disabilities.

It is not inevitable, however, that such a disadvantage need result in the person suffering any number of privations, including a loss of power relative to the power of others who are more advantaged. The hurtful domination of people with disabilities by others has to be looked upon as something that is socially constructed, rather than innate, since it is absolutely not necessary or invariable that those who possess advantages will exploit them to the detriment of the person with a disability. A change in key perceptions can greatly level the playing field.

Irrespective of what people with disabilities do to help themselves in these circumstances, it is important to recognize that those with greater power should accept responsibility for the fact that the hurtful exploitation and disempowerment of (disproportionately) vulnerable people reflects their own particular understanding and choices regarding how they use such power. It is true that such elective personal habits in the use of power are deeply conditioned by one’s socialization, but this does not take away from the fact that they are clearly learned behavior that could be subject to change, given more favourable conditions in the social environment.

For reflective and concerned leaders who seek to address and overcome such learned patterns i.e.prejudice, it is important that such habits be questioned and replaced by more adaptive behavior. Perhaps one of the primary and fundamental personal responses would be the self-conscious cultivation of a more acute and informed appreciation of the essence of what happens to people when they are rendered to be uninfluential in their own lives and held hostage to the will and preferences of others. It is very easy to unwittingly lack insight into and concern for the experience of others. This can only be reversed by a deliberate commitment to try to comprehend the experiences of others. In this, it is useful to consider what it is that might permit one to grow in this direction. Obviously, some attitudes will be more fruitful than others as to whether one can be enlightened to a degree or not. Surely, the most fundamental of tasks for leaders is to be sure that they do indeed care enough to seek to properly understand the adverse conditions of life faced by people with disabilities. This would require of such leaders a willingness to submit themselves to people with disabilities with a sincere desire to be educated by what their lives and struggles reveal. This would hold true even for leaders who are themselves people who live with a disability, since it is always arrogant to presume to understand others without taking the time to actually know them.

It is interesting to note, in this regard, that those with power often tend to take it for granted since, for them, power is not the same problem it is for those who lack it. Thus, it is to be expected that the actual functioning of power may often be more obscure to those who have it compared to those who are more perversely affected by it. Such unconsciousness about the true nature of how power is actually used, may well be reinforced by socially influential ideologies that mask what is actually happening as to the uses of power. This can clearly be seen in the case of many agency ideologies that blithely claim that consumer/service user needs and wishes are the sole factor that drives the agency, when clearly all sorts of other needs, parties and agendas are also at work and may be more influential in the end. The tendency to reflexively bestow virtue on oneself is not a good measure of whether one actually has such virtue, so much as a preference for a positive self – image, even when not deserved.

This pursuit of a desire to learn and be made aware is unlikely to be particularly empowering for people with disabilities if the seeker remains unwilling to be changed by what people reveal to them. Consequently, a further resolve would be needed from such aspiring leaders that they not simply become educated to the privations of others for its own sake, as this would be a peculiarly voyeuristic exercise. What is needed is that the seeker be willing to take seriously the people and the issues they face in their lives. This listening with a purposeful intent to be changed by what one hears, puts in place the necessary preconditions for people with disabilities to be able to gain influence with such persons. Such influence would not be realistic with people who have let themselves become indifferent. This proposed ethic of a commitment to be influenced by persons with disabilities is not a simple matter of mouthing such sentiments. It would require of the person concerned a substantial degree of authenticity in regards to being open, educable and mobilized by whatever worthy issues may emerge.

If this attitude is present in an authentic way, it then becomes possible for a type of (empowering) alliance between such leaders and people with disabilities to occur inclusing instances where the leaders are persons who live with a disability. This would be because such a leader has resolved to question how their power or that of others is used relative to the more vulnerable party i.e. persons with disabilities. From such an ethically based premise will come any number of opportunities to rectify the things that lead to the frustration and powerlessness that comes when one's voice is ignored and when others have disproportionate influence.

Such an alliance very much needs to be predicated on the ethic that power must be used to enable rather than to dominate persons with disabilities. Thus the pivotal issue is not the comparative difference in the amount of power of each party but rather how power is used. This is, by definition, something that will be governed by specific ethics and values (whether consciously recognized or not) and the key point is whether the right ones are prevailing. Such a view does not preclude efforts to equalize power, as this may often be possible to some degree, but rather to put in place a higher obligation to use power in a way that does not work against those with less power. In other words, to create the conditions whereby power is present as a factor, but one that has **ultimately** little bearing on the well being and best interests of persons with disabilities.

The achieving of these kinds of changes is not likely to come about instantly, as social change is hardly solely just a matter of good intentions or good beginnings. This raises the obvious question of whether such alliances are likely to stand the rigors and demands on them that come with the stresses of social struggle. This is the "walk the walk" test of whether any leader maintains their integrity in terms of the implied obligation to not compromise the interests of people with disabilities. This is a difficult challenge at the best of times because of the strength of the many legitimate and not so legitimate interests that are always at work in the field. Still, it is important to factor these in, as they relate to the question of strengthening the voice and influence of persons with disabilities. After all, it is often in regards to these many powerful interests that the influence of persons with disabilities is so minimal. Since this implies an ongoing condition of struggle, it is crucial that such alliances be seen as being entirely provisional, since each new challenge contains the possibility of the derailment of the alliance.

The human service systems should not be thought of as existing solely to satisfy the needs of the named client group, as this would grossly distort the evident fact that such systems serve the needs and interests of all sorts of parties other than those of the "official" or nominal client. It is crucial that it be recognized that these interests are always present and may exert their influence in ways that act to prejudice those of persons with disabilities, even when this is not particularly intentional or conscious. The task of leaders is, in the first instance, to ensure that accommodations between the many interests at work in the field can occur that favor the relative strength and influence of persons with disabilities. This is not the same as saying that those with greater power and persons with disabilities should or could have equal power. Such a remedy presupposes the feasibility of the utopian possibility of the elimination of all human advantages. What is suggested here is that there could be a leadership ethic conceived and embraced that strives to minimize any disempowering consequences for people with disabilities that may come because of the way power is used. Though such "*real politique*" considerations my offend many people of principle, they are nonetheless inescapable realities that ulrimately require a positive leadership response.

This perspective ,shifts the emphasis for leadership from the focus on tinkering with power imbalances to the deeper problem of the ethics of the use of power. Power can be used for good and therefore such power might well be used to strengthen the hand of persons with disabilities rather than diminish it. This is the essential way that alliances work in that the parties in an alliance combine their resources for greater effect. Perhaps in some instances, this effect could go as far as to render the question of power to be one that is largely irrelevant if the needs, interests and influence of persons with disabilities are being dealt with fairly. Power used well renders power to be an asset of people with disabilities even where they do not entirely control such power. It is inevitable that there will always be innumerable sources of independent power that would be beyond the scope of persons with disabilities to control and therefore a strategy is needed that would confront the issues at work in the use of independent power exercised by non disabled persons.

While many people might see the remedy to be simply one of persons with disabilities acquiring more power and solely exercising it without the need to reference the (other) powers of the world, it is important to see where such an impulse would lead. It would lead to a complete reliance on making persons with disabilities more powerful than the forces that are greater in strength than they are. In the first instance, this is simply not possible or realistic, even if it were what people thought they desired i.e. omnipotence is not an option. Naturally, there would be many instances in which given individuals could be strengthened to be more powerful in any number of ways, but this would merely shift any power imbalances a matter of degree. Additionally, it would inevitably lead to the tactical preoccupation with the enablement of persons with disabilities to become more combative relative to the (injurious) exercise of power by others. This would be because the matching or overpowering of the powerful has been implicitly set as the solution. It would also seem to presume that people with disabilities would need to be their own sole defenders, since dependence on the power of others would be seen as a compromising of the independence and self-sufficiency of the power of persons with a disability.

Other options are possible that would render such a grim polarization of people to be unnecessary. These would not be predicated on such a radically improbable transfer of power, but rather would instead require that power be controlled by ethics that favor its use to the advantage of people with disabilities. This presupposes that it is realistic to expect that alliances can be forged between people with disabilities and others who would want to throw their lot in with the struggle of persons with disabilities to get better life options. It would be these alliances and constituencies that would seek an honorable use of power relative to (powerful) interests whose use of power is unhelpful to people with disabilities. Such alliances would be possible even when the majority of society remained indifferent providing that allies existed and were willing to do what they could. Such alliances would not be dependent on achieving wholesale systematic social change, even if this were practical, since they would simply do what they could do at a given juncture. The role of leaders would be to promote and participate in such alliances…to the extent that this was possible at a point in time.

It is very unlikely that the notion of strengthening the voice and influence of persons with disabilities can be anything but a strategy for the relative empowerment of persons with disabilities, since acquiring absolute power and control is not feasible. The danger is that such recognition might leave some people unwilling to do the many things that would substantively advance the situation of people with disabilities because any gains would only be relative improvements. The temptation to want ever more broader and systematic influence is understandable, but it needs to be tempered by some sense of what might constitute the normal limits on personal influence that most people experience. In this sense, it would seem that the standard of acceptability as to what is a reasonable level of personal influence would need to be that which most non disabled citizens would consider adequate for themselves. Otherwise, the claim from persons with disabilities would have to be for an extraordinary level of influence and control that is not available to most citizens. Such an elitist claim on society seems unnecessary and unproductive if persons with disabilities can get their needs met with only normative amounts of power.

The difficulty that people with disabilities face is that they are not accorded normative rights and prerogatives on a persistent basis and thus do not have a fair chance to assert their influence. The normative method for justly advancing one’s interests is through the negotiation of these interests rather than being unilaterally told what to accept or do by others. The task of leaders is to bring about the conditions of fairness that would assure that people with disabilities could be part of the process of negotiating the important matters in their lives, notwithstanding the supports some may need for this task. This means that leaders must be particularly scrupulous in asserting the necessity that persons with disabilities be seen as deserving of the degree of autonomy, control and influence that most ordinary people insist upon.

This would also hold true at the collective level, where it should be expected that groups representative of the voice(s) of people with disabilities be granted the same standing, access and courtesies that other organized voices in the community consider to be essential. It serves no purpose to have such groups only to have people ignore them. Key leaders therefore need to develop the ethic of a standard of equitable presence and participation of the voices of persons with disabilities in the various fora of the field. This is not an obligation to offer preference for the views of such groups once they are expressed, but rather a commitment to ensuring that such voices are heard as a matter of normative conduct. Why this may constitute leadership is likely to be revealed in the effort and alertness it takes to overcome the habits of paternalism and exclusion that so massively influence the behavior of privileged groups in regards to socially devalued groups.

The implications of this ethic for how services are organized and operated are enormous, as it would mean starting from the very untypical premise that such services submit to the much more challenging role of persons with disabilities as active players in their own lives as well as co-designers and implementers of service practice to the extent that this is achievable at any point. Even now, we can see many examples of good faith efforts to deal directly and forthrightly with the aspirations of people with disabilities and their supporters to gain influence in their lives and we must yield to the prospect that this could become increasingly more common and practical should the sincerity of the effort be maintained. Nevertheless, we will still need leaders of all kinds to model such an ethic and to catalyze the reluctant to go further.

C) Encouragement of Improved Social Integration

Until relatively recently it has been common for people with disabilities to be found at the margins of community or entirely excluded in “special” encampments of various kinds which functioned to oversee their exclusion from the broader community. This phenomenon was often portrayed back to the larger community as being a benign but necessary strategy in the best interests of the persons themselves or perhaps their families. Human service professionals were deeply implicated in the rationalizing of such practices and in the mistreatments that were perpetrated on the excluded people themselves. The vast bulk of society could quite rightly claim that they were merely complying with the advice of trusted professionals in their acquiescence to the involuntary segregation of this class of people.

This began to change with the arrival into the field of the influence of post second world war families that saw their children with disabilities as being better off at home with their families if only the means to make this practical were developed. This impulse to maintain persons with disabilities within the heart of the major social institution of the family provided the moral and political foundations for what would later come to be the community services that now dominate late twentieth and early twenty first century service systems. This beachhead was greatly expanded by the normalization ideas that came to emanate from Scandinavia in the 1960's through family advocacy circles, dissident professionals and activist governmental figures involved in expanding the emergent welfare state. Later came influences from rights activists, consumer advocates, and community minded professionals and families.

The direction that emerged from these seemingly slow social processes has been unrelentingly in the direction of greater social integration. Much of the energy, though, has been directed at community service reform and, in particular, deinstitutionalizations of one kind or another. More precisely, these were exercises aimed at both the desegregation and decongregation of people with disabilities. While these have had the agreeable result of enabling many thousands of people to either rejoin the broader community or gain greater access to community, the extent to which this has occurred has been a disappointment to many of those involved. Not untypically, people with disabilities are still relatively socially isolated compared to their peers who do not live with a disability. This is partly a commentary on their degree of (achieved) social involvement in community life, but perhaps even more so on the extent to which they are satisfied within the arena of personal relationship. Most notably, there is a sense that such relationships and membership in "ordinary" community groups are not happening to the degree that might be normative for others.

To the credit of the field this lack has been noted and much has been done to raise awareness of the struggle and to pioneer various approaches to advancing the situation. Nonetheless, these needs for relationship, social acceptance and belonging still remain unmet in people's lives. The task of leaders in the alleviation of these needs is not well formulated and this makes progress on the issues to be more unlikely. A key recognition that underpins any response to this challenge is the necessity to appreciate that what is at issue is very much in the domain of the personal, though this needn't always mean the more private aspects of personal life. This is most evident in the area of community involvement, where what is at issue may be very much the degree to which an ethic of inclusive conduct in regards to people with disabilities can be learned, introduced and reinforced within community life. It is noteworthy that this must be undertaken in the context of community groups and settings over which the "field" of disability has no authority and in which the voluntary participation of community members within social integration is the norm and ought to be preserved as such.

This presents an unprecedented challenge to the "field" to adapt the meaning of what the "field" could or should be. This was less an issue when the focus of the field was developmental or custodial interventions. i.e. the production of formal services. These remain central to the core work of community services, but they are less relevant as one gets closer to what might be called "community work". Such "work" is indeed work, but it is rarely recognized as being a key element of the "essential" work of the field relative to its better-legitimated developmental and custodial competitors. In most instances the goals of community work are heralded as unarguably desirable, but the means for their achievement are typically very poorly valued and resourced. This can be seen in the weak support for activities oriented to people's social lives in comparison to their other needs.

It would be tempting to suggest that this is predominantly the result of the continued social devaluation of people with disabilities within society, but this would mask a quite remediable obstacle that lurks in the mix. This is the fact that the field and its leaders do not largely know, at this point, how to influence the community to achieve the social integration and relationship aims they have recently upheld. They lack the sorts of compellingly useful theories that would increase the likelihood of progressive methods appearing. Even the most prominent of the proponents of "inclusion"(whatever it may mean) offer little methodological guidance despite their ample exhortations to proceed. This is largely due to the relatively primitive nature of the theories and assumptions that underlie the "practice" of community integration. It is clear that the field has the desire to progress on these matters but this is unlikely to occur as rapidly if there is not a certain gravity given to the limitations of theory (and hence practice) in regards to community work.

Even if it were clearly understood what must be done to make community "work" more potent in terms of its results in people's lives there still would remain the challenge of giving such "work" the support it might need in terms of human and financial resources. This is quite apart from crucial matters of legitimation and priority relative to other matters in the field itself. Leaders are going to be critical in keeping the issue in play and ensuring that opportunities to proceed are sanctioned and protected. This is unlikely to occur if these same leaders are themselves confused as to what such community work should or could look like. This may be helped a great deal by such leaders becoming better students of the process of social integration themselves. Staying close to the lives and experiences of persons with disabilities and the people close to them can accomplish this to some degree. Expert leaders are not needed so much as informed ones. It is also important to note that small and apparently unimportant ordinary persons in this regard are doing much of the seemingly most potent “work” despite their meagre status relative to others in the field and in the formal service systems. Thus, the answers we may become most dependent on for illumination may already be amongst us in the unrecognized empiricism of people experimenting and succeeding within ordinary life.

A further challenge would rest with the need to alter the fields formalistic, bureaucratized and professionalized culture to allow for the emergence of new classes of contributors and partnerships that are voluntary, “in the community” as opposed to principally in the service system ethos, and operating from commitments and assumptions that are more appropriate for community “work”. If one is to help make a local community organization more welcoming of persons with disabilities, it may well be that the key players are (voluntary) members of such groups and communities rather than (paid) service workers. This implies that community initiatives are going to need their own paradigmatic assumptions and methodologies and these need to be able to be developed and understood as well as integrated in some way into the a different vision of the “field” and its core tasks.

It is predictable and already apparent that not everything called community work or community integration is of great quality simply because it exists and claims to be useful. In many instances, just hiding behind the goal of community integration is enough protection to ensure that community work which is not efficacious gets passed off as “needed”, simply because its apparent goals are the right ones. This is compounded by the fact that the state of the art is so elementary that simply naming something as “community building”; “community development”, or “inclusion” is taken as evidence that it is benign and helpful. Thus a challenge for leaders will be to begin the process of becoming astute as to what is substance and what is not in this emergent domain. This will be helped by better theory and analysis, but it can also be helped by careful attention to the claims, agendas and actual results of all that is done in the name of better social integration.

This is not one of those situations that deserve the usual nostrums of more research, more conferences and more journal articles, though one could see a role for these. What is at stake is not merely the question of improved methods and theory, but rather the much more crucial matter as to whether the humanity of people with disabilities is ultimately nurtured or ignored by the field and by society. To ignore the importance of belonging, acceptance and personal relationship is to overlook some of the most crucial senses of what it means to be human. The profound longings for love, acceptance and intimacy are, naturally, as present in people with disabilities as they are in all people and to overlook this in terms of the priorities of the field is a startling revelation of how much the field's relevance has strayed from the real issues of people's lives.

D) Challenging and Transforming The Relevance of Services

A good deal of attention in the last several decades has gone into the task of creating, financing and institutionalizing community services. This has partly been driven by demands for such an expansion based on the premise that services were somehow "good" in general and that more of them would therefore be better. This, in turn, has led to the inevitable growth of vested interests of all kinds that now pervade the formal service world. The needs of the many parties involved invariably distort the agendas of such services towards priorities other than those of the service user. This is an easily discerned process and one that can readily result in the diminution of the needs and priorities of service users amongst the competing demands of the usually more powerful interests at play. It is important, therefore, that leaders recognize that formal services do not solely exist to benefit the needs of consumers, as is so often naively or uncritically claimed. It is important to presume that the modern formal services and systems are societal in how they function and thus commonly serve interests and social policies that may often be obscured by the self-congratulatory and pious rhetoric that envelops them.

Once services begin to submit to the task of meeting the needs of parties other than those of the service user then it is unavoidable that they will soon begin to lose whatever degree of coherence as agents of service or assistance for the service user that they have achieved. This could presuppose, quite undeservedly, that most services would "work" if it were not for the distraction of vested interests. i.e. that they are normatively internally programmatically coherent. Nonetheless, there still remains the fact of the necessity for services to be enabled to remain free enough in the midst of the play of interests to repeatedly place the needs of those to be assisted as central to the calculation and actual operationalization of priorities within that service. This fight for the dominant focus of the service to be (back) on the needs of the intended service beneficiary is a huge task for leaders, whether those leaders are advocates, funders, families, consumers, staff, or managers.

This task is made all the more difficult by the fact that the state of the art in formal services is such that many services are not particularly of good quality or helpful to the lives of those who rely on them. In some instances, the services may even be detrimental to their users needs even if the (non disabled) operators of services mean well. This is because the state of the art and the state of the practice in community services are hugely variable. This then raises the challenge for (interested) leaders of initially trying to discern which services "work" and to what degree and, subsequently, the task of doing something about it. This, in turn, then leads to the various complex tasks associated with transforming or replacing services, such that service users are enabled to have access to services that are proportionately more beneficial. In many instances, the principal answer to the needs of people may rest with measures and parties outside formal services and thus the pathways to their appropriate utilization will need to be identified and pursued. This scenario underlies the necessity that there be leaders present who can successfully take on the various roles associated with trying to make formal services more relevant overall including, at times, the elimination of services that are fatally irrelevant to the needs of people.

Implied in this leadership challenge is that there is a necessity to treat services as being potentially suspect. This tends to go against the premise of previous decades, which essentially gave services the benefit of the doubt. It also implies the hugely difficult, but necessary responsibility for leaders to discern what might be useful service reform from misguided transformational processes. This is a very complex task, but one that is very crucial when one sees the many countless failed reforms, restructurings and regrettable "paradigm shifts" that we are constantly asked to believe will lead to progress. The "reform fatigue" that helps makes so many people end up a little jaded could be much helped if reform itself were tested for relevance particularly at a point where it could be rethought.

If there is ever to be the resources for the support of highly relevant services, it must come from a commitment to gradually divest existing service empires that have irretrievably succumbed to irrelevancy in how they use their resources. If this were done well, then it would then permit these resources to be used elsewhere for greater good. This task then merges the problem of vested interests (and probably powerfully entrenched ones at that) and the task of valid service reform. This creates the technical conditions for a "politics of reform" that will need to be taken up at both the political and programmatic level. The sheer difficulty of such a strategic undertaking suggests the need for leaders that are not only programmatically sound, as they would also need to have considerable values and moral integrity to take up such politics in the first place. Such “moral leadership”, or what some might call values based leadership, should not be presumed to be in ample supply given the huge size of the problems to be faced. Leaders who overestimate themselves in regard to the perils of such a challenge could readily become the broken flotsam and jetsam of failed change agents who have worsened such conditions in the name of repairing them.

It cannot be presumed that the ever increasing resources that have fueled the expansion of the field will continue to be available in the regularly expanding way that has characterized recent decades overall. Thus, it becomes all that more important that a high standard of astute utilization of limited resources be applied to the question of the ultimate relevance of existing services to the actual needs of the people who rely on them. This “raising of the bar” will be very divisive, but it may, nonetheless, be a crucial indicator of whether the field has the right to claim that it is acting in the best interests and well being of the people that society has entrusted it to benefit. In many ways, the taking up of this challenge might be thought of as a key element of the moral renewal of the field as opposed to simply a programmatic updating. The reason for this goes to the heart of whether the field is sufficiently honest about what indeed works.

E) The Renewal and Evolution of the Field

It is a common experience in the lives of individuals that they must take time periodically to refresh themselves after a period of intense activity or challenge. Often, this may take the form of rest or some other replenishment, as the case may be. In other instances, the challenge may not be to simply recover from a demanding period, it may extend itself into questions related to whether the tasks undertaken were done in an inspired way. The desire to take things to a newer or better level may reflect not only a form of renewal it may also be a catalyst for the evolution of practice and perspective. Where renewal and evolution are taken seriously as integral to advancement and progress, one could well see that the state of the art would improve. If one applies this sort of thinking to the disability field and the broad social movements it represents, then it becomes evident that the same considerations might well apply in terms of whether the field maintains its “edge” or begins to slip into decline or decadence. A sign of this would be that the field has stalled in its forward progress and has not adequately addressed its need for renewed vitality and evolution.

This sort of decline would be most evident in the failure of the field to produce new leaders that act to challenge the field to advance in the face of institutional pressures to maintain and exalt an unimpressive status quo. When the existing leaders become too comfortable, too unchallenged in their doctrines and complacent in the face of the unaddressed needs of people with disabilities, it is not hard to imagine that declines in the moral, technical and intellectual aspects of the field are imminent. The preference of the leaders for coasting along on the progress already forged rather than taking on of emergent challenges would signal a failure to rouse people to the tasks that assure the forward momentum of the field. It is important to be able to perceive whether this is the case and whether there could be efforts at renewal undertaken that would assure that the field evolved.

Perhaps the most critical dimension of this problem of renewal would be the attraction into leadership roles of new leaders to continue to appropriately “build a fire” under the leadership establishment. Perhaps even more so, would be the intentional cultivation of young leaders to one day become the replacement generation of the leaders who are now in the fullness of their power and contributions. Yet at the beginning of the new century we see a field in which there are few investments being made in the recruitment and formation of talented young leaders to be ready to take up the challenges as the existing leaders leave the field or weary of the struggles of carrying a progressive agenda forward. The huge cohort of leaders who built and currently preside over the community living movement will, in a few short years, be passing from the field, yet this is neither perceived nor dealt with as the crisis it really is. This emergent crisis is apparent not just in these demographic dimensions, but also in terms of assuring the preservation of the gains of the past decades. The charting and pursuit of an even more promising future for persons with disabilities is well nigh impossible unless there is the attention to the investments needed to ensure that a future cohort of leaders arises to take up the work.

Another key dimension of renewal and evolution would be in the investments made in the critical thinking needed to analyze the shortcomings of what is on hand today with a view to identifying the next needed round of experimentation and innovation. This typically begins with a willingness to be critical of today’s level of progress in the hope of updating what will be tomorrow’s concerns and practices. This is not dissent and uneasiness for their own sake, but rather for the practical reason that inferior thinking and practices will not advantage people with disabilities. Progress measured in terms of the advances in the lives of person’s with disabilities seems a very defensible measure of progress. If the existing leaders of the day do not act upon the challenges of poor practice and thinking, then it is not hard to imagine the rise of the kinds of counter movements that so typically provide a crucial source of renewal for the field. These, themselves, require leadership, often from initially non-legitimized sources. The question will be whether the field’s established leaders see the wisdom of tapping into the renewal potential hidden in the capacities of people who challenge today’s orthodoxies.

One key area of fallout that will be witnessed is in the decline of innovators as being central to the field. This will, of course, be in favor of people whose identity is much more concerned with institutional respectability, expedience and the maintenance of current vested interests. This colonization of the field by persons whose agendas are not aligned with a forward vision for persons with disabilities would quickly lead to the stabilization of the field at today’s state of the art. These phenomena would bring with it all the consequences that come with the halt of forward thinking and movement. Were there to be an antidote to this it would need to be the care and cultivation of innovators. One could expect that this would engender yet more of the vital experimentation that is associated with the best of collaboration with people with disabilities, research and development and grass roots insurgencies. This is not only a question solely of the “official” efforts at innovation it also relates to the support of the kind of independent minded sources of innovation as may be seen in think tanks, consumer and family advocacy, independent institutes, support for intellectual challenges and the countenance of non mainstream voices by mainstream bodies. In short, creating a preference for weak boundaries in the hope that openness to useful change can be fostered.

It is unlikely that leaders can expect such an orientation to evolution and renewal to take place if there is not put in place the kind of thinking that permits people to see the value that can be obtained by what is, admittedly, a process that is intended to be disturbing to the comfort levels of many people. In order for people to embrace change there needs to first be their persuasion that the whole ethic is justified on moral as well as other grounds. Otherwise there would be no context for the sacrifices that are likely to be involved in meeting the human costs of change. This suggests the creation of strategies oriented to building the conviction that the life circumstances of persons with disabilities are currently unsatisfactory and that they can be changed for the better. This must be done in close alliance with the people whose lives are at issue in the debate and with recognition of the extent that they themselves seek further progress. Such a broad alliance of like-minded people from all sorts of roles in the field need not be formalized but it should be sought and cultivated as being an essential foundation for a shared ethic of evolution in the field.

CONCLUSION

While it is daunting to consider just the challenges contained in this brief examination of the possible role of leadership in the field of disability, there are many more challenges not mentioned here. Though this is sobering, it does, nonetheless, underline the crucial role that leadership can play in the field and compellingly argues for a commitment to investments in the various forms of leadership that are needed. This is not a matter of esoteric curiosity, as the consequences of not making such investments are already evident in the many signs of the growing decadence of the field relative to the unmet needs and hopes of persons with disabilities. This is not an inevitable decline that is foreordained, but rather a decline that can be predicted when too few people take the future seriously in today's decisions. There will be a correlation between what we do today and the longer-term prospects for the field. Even the simple contemplation of the theoretical possibility of the field rapidly collapsing could serve to make the connection more apparent between leadership and the field's progress or lack of it. This commentary is not advanced on the basis that the leadership challenges cannot be met, but rather to underline that they have been met on other occasions in the field's history and could well be taken up again if we notice their importance. If we do not, then we will soon begin to witness, on a very widespread basis what happens when leadership is inadequate. We must, nevertheless, continue to advance these leadership issues, as there is still time to make a difference for the good.

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