

**Some Observations on Several  
Enduring and Decisive Leadership Challenges  
in the Field of Disability**

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## 1 General Observations

The disability “field” is much more than the current professions that work in it and the organizations that define much of its activities. It is composed of a variety 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 only through deliberative authorities or formal coordinative bodies. What at its heart makes a social movement is shared frameworks of values and ideologies. These serve to unite what otherwise would be unrelated

personal actions into collective social change. 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.

“Leadership” can be thought of as arising both from the actions of individual persons and from the collective effects of their efforts when these are combined with others. In this sense it is an effect that most fundamentally arises from people more than from organisations. Hence, it is very much part of the capacities or “human capital” of a field and therefore an asset that may be either wisely cultivated or squandered by the heedless. 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. What will be attempted here is to identify some of the “core” or pivotal challenges over which leaders in the field must prevail if the field is to avoid decline. These are challenges that are so persistent that they stand as crucial tests of whether the field will progress or succumb to decline.

The concept of a “leadership challenge” refers to key tasks facing leaders, that is the tasks that leaders ought, 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 assurance that such advances will inevitably occur as beneficial progress is not a “given” even if it is needed or sought. Leadership in this context emerges as the capacity to establish directions and purposes that move a field towards goals that favour its valid interests.

Leaders are the people who provide the catalytic force that seeks whatever opportunities towards these ends that can be created or pursued. “Leaders” does not necessarily mean persons who occupy formal roles of leadership, as many such incumbents may not actually be providing leadership. Leadership can come from any number of people who lack formal authority but who nonetheless have a measure 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, neighbours and many others.

The need for social movements often arises because the way forward is blocked by the established authorities. This prompts into existence ways of acting that go outside of conventional pathways. It also usually propelled by calls for social change to accommodate a new vision of what is possible.

Whether such proposed changes prove to be ultimately beneficial, moral and productive is inherently a values rather than a leadership question. Nevertheless, even these metaphysical questions will be deeply dependent on the actions of leadership if these matters are to be properly raised and settled in any public and enduring way. The act of getting people to engage important questions so that these can be suitably addressed is often a crucial part of the process of leadership. This is because unity of purpose is essential to the process of people working together.

## **2 Establishing Shared Vision, Values and Moral Purposes**

It is not possible for humans to live in a world without definition and therefore the way in which meaning is made in the world is central to the behaviours in which people engage. Leadership is inevitably part and parcel of the process of bringing about shared agreement amongst collectives of people as to what they will care about and commit to. There will always be incessant challenges to the priorities of what will dominate the focus and best energies of any field. These might come from both outside and inside the field as conditions unfold. Still, it will invariably be the task of leadership to help define what will be considered important. Leaders do not solely determine the outcome, but they typically participate in influencing people about the content of these eventual value decisions. Leaders are both constrained and authorized by the consensus that exists about 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.

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 exclusive authors of vision though this does occasionally occur. More typically, leaders help people form, embrace and uphold a vision so that action can eventually take place. Leaders who lack vision will find it very difficult to make progress, as they have no direction in which to proceed. Similarly, leaders who have weak or deprived vision will also fail to generate progress as their vision offers little that is advantageous. Thus a correlation exists between the quality of vision and the quality of leadership.

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 prove to be mistaken or even damaging. The test of leadership vision is whether the vision opens up positive potentials for people or not. Notably, not all visions are ultimately 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 not only to be part of creating vision but also asking what are the elements of vision that are 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 of leadership. It will certainly distinguish leaders who matter. Not uncommonly, leaders that do not challenge us to be and do the right thing will contribute to complacency and decline, whilst those which encourage us to stretch for the good and beneficial (relative to the needs of persons with disabilities) will advance the field.

It is quite clear that there are leaders 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 rest solely on their technical 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 people with disabilities 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. Another more recent tragedy will undoubtedly prove to be the unfettered use of psychoactive drugs as a behaviour management tool. At the time of the enactment of these policies there was certainly little enough opposition from the field. This lack of moral clarity thereby permitted the unchallenged implementation of these crimes by technically competent but otherwise immoral leaders and populaces.

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 public stance (or lack of it) in the face of the values challenges that exist at the time of their existence. The current persistently negative statistics on the level of reported abuse of persons with disabilities *within* community life represents one such instance of a key leadership “values challenge”. Despite the enshrinement of “community living” as being desirable it still remains for people with disabilities a life in which they are at comparably greater risk of being mistreated than their fellow citizens. Hence, the “leadership challenge” is to find ways to make community living a far more just and secure existence than we have achieved thus far.

This “values leadership challenge” of supporting judgments 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 unrealised 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, particularly

where there had been very little of it in recent generations. The very fact that society needs to be continually challenged to make this goal more real is an indication of the inherent difficulty of offering leadership that disturbs the social order.

The second broad aspect of the “values leadership challenge” is to identify and confront 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 with regard 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 be created for persons with disabilities that would permit them to be treated as having the same rights as their fellow citizens. Curiously, many thousands of people with disabilities are denied medical care comparable to that given to their fellow citizens through the assignment to them of “do not resuscitate” orders in hospital settings based simply upon their status as disabled rather than upon the merits of the possible treatments available. In this, a “DNR” order on a medical chart becomes the authorizer of a “do not try hard” or “death would be better” mentality that unmask the profound lack of value that society places on their lives. Suffering from

otherwise treatable conditions or facilitated premature dying is hardly a pattern that should leave conscientious advocates or leaders unchallenged.

The third aspect is to strengthen the process of engagement of people with key values questions. 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 them. This can be seen in the example of well-intentioned people unwittingly depriving other people of their ultimate potential for social integration in the name of safeguarding them or protecting their happiness. Many programs that involuntarily and unnecessarily sequester people with disabilities *within* community (usually labelled “special” this or that) need to be questioned with as much rigor today as were the residential institutions that are now in disfavour. It is notable that these were seen as being equally benign in their day. What needs to be appreciated is the widespread social process of values challenge and reconsideration that underpinned the ability of society to change its view of what could be possible for the lives of people with disabilities.

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. Equally, a field that is too assured in its assumptions and dogma is already imperiled by the complacency, habits and lack of mindfulness that these bring. A much better ethic for a human service field that wishes to stay at the “cutting edge” would be for its leaders to embrace the familiar saying of “comfort the afflicted and afflict the comfortable”. What follows are a sample of the core issues the field now needs to address if it is to remain true to the best interests of people with disabilities.

### **3 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. As far 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 recent recognition nevertheless does raise serious questions as to what would constitute a judicious response from leaders.

All things being equal it is likely that at least some small number of persons with disabilities may attain a considerable measure of personal power notwithstanding the many predictable obstacles that this might involve. It is also by contrast readily apparent that many people with disabilities are strikingly limited by their disability in their capacities to gain and exercise worldly power. 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 and socially favoured.

For reflective and concerned leaders who seek to address this vulnerability to domination by others leadership must begin with a desire to be enlightened as to what relative powerlessness does to a person. This requires of such leaders a willingness to submit themselves to be educated by people with disabilities. This holds 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 should be carefully noted that those with power often tend to take power for granted since, for them, power is not the same problem it is for those who lack it. 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 power 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 needs and wishes are the sole factor that drives the agency when clearly all sorts of other needs, parties and agendas are at work and influential.

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. 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. It requires of the leader a substantial degree of authenticity with regard 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. This is because such a leader has resolved to question how their power or that of others is used relative to the more vulnerable party, that is 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 upon 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 ethics and values are prevailing. Such a view does not preclude efforts to equalize power, as this is often possible to a considerable 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 little ultimate bearing on the well being and best interests 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 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 disempowering consequences for people with disabilities that may come because of the way power is used. This 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 used well renders power to be an asset of people with disabilities even where they do not ultimately control such power. It is a certainty that there will always be sources

of independent power that are beyond the scope of persons with disabilities to control.

Many people might see the remedy to be simply one of persons with disabilities acquiring so much power that they can exercise it without the need to reference the other independent powers of the world. This premise would lead to a reliance on making persons with disabilities more powerful than the forces they are likely to encounter. This is not realistic – omnipotence is not a practical option. Also, it would lead to the tactical preoccupation for persons with disabilities to become more combative relative to the (injurious) exercise of power by others. This is 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 compromising the independence and power related self-sufficiency of the power of persons with a disability.

Another option is possible that would render such a grim polarization of people to be unnecessary and which is not predicated on such a radically improbable transfer of power. This would require that power be subordinated to ethics that favour its use to the advantage of people with disabilities – that is an alliance governed by an ethic of “right

relationship”, that is an honourable, morally defensible, relationship. Such alliances would be possible even when the majority of society remained indifferent or opposed providing that such 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 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.

The implications of this ethic for how services and community life operate are enormous as it means starting from the very untypical premise that society submit to persons with disabilities as active players in their own lives as well as co-designers and implementers of service practice. 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. 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 catalyse the reluctant to go further.

## **4 The Work of Improving The Quality of Life for People With Disabilities Within Communities**

The field has very gradually moved unrelentingly in the direction of greater social integration or what many call community living or inclusion. Much of the energy has been directed at community service reform and most notably 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 are not happening to the degree that might be normative for others.

It is noteworthy that this goal of social integration must be undertaken in the context of citizens, community groups and settings over

which the “field” of disability has no authority. 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 principally developmental or custodial. These concerns 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 because much of it is done by “ordinary” citizens as part of everyday life. This is in contrast to the work of paid employees and professionals that many consider to be the “real” field.

Most leaders in the field are themselves very unclear both about what theories should guide the achievement of social integration and about what “community work” should or could look like. This may be helped by such leaders becoming better students of the process of social integration themselves. It is important to note that “small” and apparently unimportant ordinary persons 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. The theory and practice answers we are seeking as to what “works” to have people better included in their communities may not come solely from professionalised “experts” but perhaps

proportionately more from everyday citizens. If so, a fundamental challenge would be to alter the field's formalistic, bureaucratized and professionalized culture to allow for the emergence of new classes of contributors and partnerships. These would likely be voluntary and "in the community" as opposed to principally in the paid service system ethos. Such community initiatives are going to need their own paradigmatic assumptions and methodologies and these need to be developed and better understood as well as integrated in some way into a quite 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 about whether the humanity of people with disabilities is 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. 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.

## **5 Challenging and Transforming the Relevance of Already Established Services**

A good deal of attention in the last several decades has gone into the task of creating, financing and institutionalising community services. This has partly been driven by demands for such an expansion based on the premise that services were 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. 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 additional interests and social policies that may often be obscured by the 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 of service they could otherwise muster. This might presuppose that most services would “work” if it were not for the distraction of vested interests – that is that they are normatively internally programmatically coherent. This

struggle for the dominant focus of the service to stay 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 quite variable and not necessarily of good quality or effective in meeting people's needs. In some instances the services may even be detrimental to their users needs.

This raises the challenge for leaders of needing to discern which services “work” and to what degree. This in turn leads to the various complex tasks associated with transforming or replacing services such that service users have services that are proportionately more beneficial. In many instances the needs of people may rest with measures and parties outside formal services and this will mean approaches that are well outside any conventional strategy of “service repair”. This underlies the necessity that there be leaders present who can successfully make formal services more relevant overall, including 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 ineffective. 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 jaded could be much helped if reform itself were tested for relevance particularly at a point where it could be rethought.

If there are 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 is done well then it will then permit these resources to be used elsewhere for greater good. In all likelihood the transformation of resources would optimally and feasibly occur through small initiatives. With time, learning to apply resources would come with experience gained through these experiments.

This leadership task merges the problem of vested interests (and probably powerfully entrenched ones at that) and the task of valid

service reform. Doing so will create 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 both programmatically sound and have sufficient 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 may readily join the many 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 fuelled 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 for whose benefit society has entrusted it. 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 for the good of people.

## **6 Strategic Investments in the Renewal and Evolution of the Field**

A key leadership question is whether the field maintains its “edge” or begins to slip into decline or decadence. A sign of this decline 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 is the attraction into leadership roles of new leaders to continue to

appropriately “build a fire” under the leadership establishment. Perhaps even more so is 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 conscious investments being made in the recruitment and formation of talented young leaders to be ready to take up the challenges as existing leaders leave the field or weary of the struggles of carrying a progressive agenda forward. The huge cohort of existing leaders who have built and now preside over the community living movement will, in a few short years, be passing from the field. This is neither perceived as, 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 and innovators arises to take up the work.

One sign of the decline of a field is when innovators are no longer central to the field. These conditions will favour people whose identity is much more concerned with institutional

respectability rather than with a forward vision for persons with disabilities. It will also freeze the field at the point of the day's state of the art, that is, it will retain the status quo of the time. This phenomenon will bring all of the consequences that result from the halt of forward thinking and movement.

The antidote to this is the deliberate cultivation of innovators and the vital experimentation that is associated with the best of collaboration with people with disabilities, research, development and grass roots insurgencies. This is not a question solely of the "official" efforts at innovation as it also relates to the support of the kind of independent minded people who animate think tanks, consumer and family advocacy, independent institutes, support for intellectual challenges and the countenance of non mainstream voices by mainstream bodies. Such innovators need an environment where their disturbing visions of a better world can gain expression – in short, creating in the field a preference for weak boundaries and orthodoxies 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 occur 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 they need persuasion that the sacrifice of today's ethic is justified on moral as well as other grounds. Otherwise there would be no context for the undoubted tribulations that are likely to be involved in meeting the human costs of change. This is impossible without the *a priori* conviction that the life circumstances of persons with disabilities are currently unsatisfactory and that they ought to 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 and scope of progress that they see for themselves. Such a broad alliance of like-minded people from all sorts of roles in the field then becomes an essential foundation for a shared ethic of evolution in the field.

## 7 Concluding Remarks

While it is sobering to consider just the few 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. This small selection of unremitting issues underlines the crucial role that leadership can play in the field and it compellingly argues for a commitment to investments in the various forms of leadership that are needed. One should not see this as just a matter of esoteric curiosity as the practical consequences of not making such investments are already evident in the many signs of growing decadence of the field if the unmet needs and hopes of persons with disabilities is our measure. This need not be an inevitable decline that is somehow preordained. Nevertheless, decline can be predicted when too few people take the future seriously in their thinking about how we conduct today's business.

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 always time to make a difference for the good.