

Them and Us?
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Drawing on a recent conversation on the Disability Research mail list/discussion group, the purpose of this article is to identify some of the stakeholders who are working and acting in the interest of people with disabilities, to explore the nature of and the reasons for some of the tensions between them, and to suggest where bridges could be built. It is a partial treatment of these issues only, a small contribution to a potentially vast debate.

The conversation, or thread, as it is called on Internet discussion groups appeared on a list maintained for disability researchers quite a number of whom appear to have direct experience of disability mainly by having a disability themselves. I identified also, in this thread, at least one parent of a person with a disability.

The discussion arose from a researcher who had a disability and who was involved, in her research institute, in the development of a disability etiquette brochure to which she objected. A parent responded by criticising “academics in ivory towers” who were “removed from the real world” which he then related to a personal situation in terms of a list of pet hates of parents of people with disabilities. These referred to things like people generally not talking to the person with a disability, but to the parent claiming they knew “what it was like” or being over-helpful.

Some participants in the discussion expressed resentment of ivory tower comments being levelled at them. The conversation then led to the position of disabled researchers in academia and the discrimination they felt within that environment such as difficulties in achieving careers equivalent to non-disabled researchers. Their dual perceived or actual roles of researcher and activist were often problematic for them.

I also noted various stakeholders, the experiences of marginalisation some of them had in common (i.e., people with disabilities and their parents), the position of disabled researchers in academia as well as the tension between researcher/activist roles. One discussion participant observed that “everyone who gets involved with disability studies is touched by the institutionalised oppression of disability studies” and wondered whether that oppression is harder “for those who have impairments and work in the disability studies field.” Another wondered whether “perhaps we are all on the same side of the fence, just in different fields.” Still others questioned whether a them-and-us attitude, as seen to be present in the discussion, was counterproductive.

The stakeholders in this debate were disability activists, researchers with and without disabilities, and parents (some fulfilling dual or triple overlapping roles). They wrote from several countries including the USA, the UK, and Australia. There were a number of important issues underlying this discussion of international interest. One issue concerned the devalued status and image of people with disabilities in our society with regards to the effects on persons and, in this case, university courses and research. A second issue related to the potential disservice to the cause(s) of people who have disabilities when the tensions between the various stakeholders apparently lead them to get stuck in their own personal contexts ignoring their commonalities. A third issue seemed to be about a tension between grassroots activists and disability researchers, with or without disabilities.

In an effort to go forward, I asked in a posting to the list whether it might be time for an international conference where we would seek to *combine* the strengths of these stakeholders with an aim of advancing the interests and needs of people with disabilities. The replies to this cyber-proposal were enthusiastic, with people asking to be “booked in, now.” I do not know whether such a conference will ever become reality, but I would like to suggest we could all make a contribution now without having to wait for such an event.

The Disability Agenda, Clarity, And Tensions

An examination of The Disability Agenda, what is on it, what should be on it, who sets it, and who should set it, may serve to find some of the tensions between the different stakeholders. It may also take us forward if not as one, great, united group with a single purpose, but perhaps several groups who are clearer about their identity and interests and who can, at least on some areas, productively work together. The result would be a better understanding of and greater respect for each other's views.

The disability agenda (that is, the list of those things that most need to be done) may to some extent often appear to be set by people with disabilities themselves, or by others closely affected by disability, as the items on their list may appear to coincide with those of political parties, governments, and funders. It is often the methodology by which these issues are to be achieved where those with power mostly wield their influence, and where the real (not always clearly identified) discrepancies between a grassroots and a government agenda appear. Cost cutting, privatisation, and treating human services as businesses-for-profit are all instances of political influence that has taken its toll on service availability - its nature, relevance, scope, and quality. It is also the case that those who are seen as most costly to the government (those who need the support most) are most likely to get least or nothing in the way of services.

For instance, in Australia, where disability advocacy is funded mainly by the Commonwealth Government (which is clearly an unwelcome responsibility for the conservative Howard Government), what are known as advocacy services (actually, they are part of a community/disability movement response) currently face government measures-by-stealth which are threatening to transform the advocacy realm into ineffective little bureaucracies. In other words, government can say it funds advocacy while seeking to ensure that radicals will not be a nuisance or political threat and that they fall in with the Government's minimalist approach to discrimination and disadvantage.

In addition the UK, the Netherlands, and other Western countries have started to reduce disability benefits. Likewise, in Australia while the disability community wants to learn, live, work, and play where everybody else does alongside their fellow citizens, our government is winding back the clock and supports segregated responses to education, accommodations, and employment. At the same time, the aptly named disability industry can usually only think of (expensive) service responses (as distinct from informal, community-embedded responses) to needs partly because that is literally its business and because it generally does not know how to respond outside its formal service paradigm on human need. The disability industry is a contributor to Western countries' Gross Domestic Product scales (GDP), the index used to indicate a nation's economic health. We all know about the overriding importance many governments attach to the state of their economies in many instances to the detriment of their most vulnerable citizens who, if they can only be consumers in name and are not seen as productive, usually get treated as useless burdens (see McKnight, 1976, 1986 Hamilton, 1994).

This is a partial description of the dominant environment wherein researchers, disabled or not, as well as grassroots activists, have to operate. It is the dominant culture that often provides the funding for research and the dilemma for researchers, at times, is whether or how often to bite the hand that feeds them. This is one point where the interests of researcher and disability activist often clash as the *real* government agenda and that of people with disabilities are in conflict. Researchers with disabilities are more likely to be badly affected by this tension because for many (perhaps more often than for non-disabled researchers) the very reason they got into research was to change something while using their talents and earning a living. The desire to achieve change combined with their heightened vulnerability - should they lose their job or be blocked in their careers - can and does make for a frustrating situation. To an extent, perhaps, the same could be true for parent-researchers. Activists or grass-rooters (including parents), on the other hand, can be seen as threats to the scholar-researcher contingent. They may embarrass this contingent when they

point to its being removed from the day-to-day realities of living with a disability and when making researchers face up to the outcomes of their work. They may, sometimes by their very presence, knock over academic Holy Grails and make emperors feel naked.

This may be painting too much of a black-and-white picture, but it serves to point out where some tensions may exist as well as some reasons for these tensions. We must identify how the dominant environment commonly affects us all. We must recognize the ways in which we are interdependent and affect each other even while we do not share all interests. This will be more productive than just looking for explanations from our own personal perspectives relevant as these are. Other reasons for these tensions that permeate our lives are to be found in the generally disadvantaged, devalued status of people with disabilities: the fear of "the other" which is still present in many ordinary citizens and the persistence of medical, economic, pity, and charity approaches to disability.

This analysis does not address tensions that sometimes exist between parents of people with disabilities and people with disabilities. For purposes of this article, it may be enough to say that the needs of the two groups are not always the same so that within disability activism, where parents also participate, there are differences that need to be bridged by listening to each others needs, views and roles.

In addition there is the overlay of global and significant cultural, environmental, and technological change whereby, inevitably, marginalised groups of people are increasingly disadvantaged notwithstanding the rhetoric about improvement and progress. All stakeholders in the disability area are touched by that marginalisation, in greater or lesser degree, whether it is about getting your needs met as a person with disability or whether it is about getting funding for disability research. Marginalisation does, however, give us all some common ground.

Further, we must re-examine the key issues in disability: what is really most needed, most urgent at this point? We should not merely reiterate the list of our demands: access-to-transport, income, education, accommodation, employment, attendant care. This list has been oft-repeated and presented to governments and other funders. We ought to examine what is *really* on the agenda now, *who* put it there and *how* that agenda diverts us from what "we" believe is really needed most. In doing this, it is important to carefully and clearly put our values, theoretical orientations, and stakeholders roles up front. Not only does that force the various stakeholders to be transparent about why they believe what they say is important, but it may also encourage stakeholders to see beyond their own context.

If one wants to build lasting bridges such openness and clarity is essential. The overlapping roles of the various stakeholders may make this task somewhat easier because they may be able to walk at least half a mile in someone else's shoes; or our job might be harder because of conflicts of interest. It will be interesting to see what emerges.

Openness and clarity is not only needed to get the various interest groups together. These attributes provide the means to arrive at common approaches to an area now rapidly growing in importance: the end-of-life and ethical issues such as euthanasia, abortion, eugenics, genetics, organ donation, do-not-resuscitate orders, disability prevention programs, safe hospitalisation, and so forth. How we declare the ways in which these issues relate to the daily lives of people with disabilities and how we guide these issues to resolution will be activities that reflect on the image and status held by people with disabilities in their communities. Depending on our position and our strength, our response will consequently help the officials decide what may "legitimately" be done to us ranging from the type and quantity of support that is offered to us, to the literal right to live. This is an important disability agenda item not always willingly taken up by activists (notable exceptions in the US and elsewhere granted).

We can only put these things firmly on the disability agenda as fundamental issues to be addressed by being firmly united around a set of common values, beliefs of the nature of the world, and of people. These are issues that cannot be adequately addressed by a group that is divided or,

for that matter, by those who say these issues are people's individual responsibilities, or who say these issues are too complex and controversial to get into, or who do not want to be tarred with certain fundamentalist brushes.

Finally, as we are talking about an international, multicultural phenomenon, it may be difficult to speak of one uniform agenda, but we may be able at least to identify a common ground based on the widespread position of heightened vulnerability, disadvantage, and devaluation that so many people with disabilities experience worldwide. We may decide to take the additional route of talking about different agendas in different nations and cultures and at regional and local levels.

Disability Theories, Intellectualism, And Divides

Some people address disability issues through a formal theory or model, such as the social construction of disability, Social Role Valorization (SRV), or a formal or informal model of social justice and human rights/disability rights. Some do not use any formal theory or model at all and just make judgements on how to act from moment to moment. Researchers mostly need a model or theory while activists often make do without any organized plan reacting from crisis to crisis and from a gut feeling. Researchers most successfully work with theories and models when they are in touch with the real need on the ground either through direct personal experience or by deliberately immersing themselves in the situation of people with disabilities. Theory, explored in isolation from the people who are affected by disability issues, can be ineffective or even harmful. Grassroots activists who have an emphasis on lurching from crisis to crisis without guiding, clearly articulated, and internalised philosophies, models, or theories, will find themselves ineffective in the long run and may self-destruct from sheer exhaustion. (That is not to say that using theory will not be exhausting, but at least you will know more about *why* you are exhausted!). There may be an answer in bringing the two emphases together while preserving the integrity of the respective roles. There are, however, some real difficulties with this.

As someone with a disability and a combined advocacy/activist and research/student background I have been accused by advocates of being an academic. To their credit, no academic has ever openly accused me of being an advocate, but I have sometimes been aware of a wariness by scholars and others with disabilities who clearly experienced glass ceilings and disempowerment in academia. Distrust between intellectuals and the people in grassroots movements is nothing new in human history, but it is sad when this happens to people with disabilities who might, in some sense, be described as members of the same class.

One reason for the tension may be the fact that many people with disabilities, and others directly affected by disability in their lives, see all academics as removed from their real world situation because numerous professionals, interviewers, and researchers may have walked in and out of their lives without being perceived as being practically helpful.

Another reason may be that some people with disabilities and their parents were seduced by the trappings (money, status, employment) of disability service systems and research institutions that employ them. Now they do not want to rock the boat too much for fear of losing what they have achieved (particularly as they do remember the alternative). For some grassroots people who have disabilities, disabled researchers have become honorary able-bodied people and are seen, therefore, as now removed from their own situation. On the other hand, some activists stand accused of being mere "briefcase carrying bureaucrats" themselves, after being allowed into the governmental corridors of power and thus escaping the real world. Some of these new bureaucrats ignored the needs of the most vulnerable, the most disadvantaged in their efforts to "get runs on the board."

Bringing together researchers and the members of the disability movement, whether disabled or not, on a regular or infrequent basis, in formal or informal or larger or smaller settings (not just one grand international conference) and in an open and honest atmosphere, may help reduce these tensions. Further, a personal connection with the lives of at least one or two ordinary people with disabilities would be valuable for disability researchers/academics in achieving a

grounding with the area of real need. Such connections need to be actively sought, if there are none presently.

Bringing together the stakeholders may also lead to some greater openness and accountability for the conduct of people who perform work in the disability area, paid or unpaid, disabled or able-bodied, researcher or grassroots activist. It may also lead to more widely understood disability theories, models, and philosophies that contribute to positive social change or at least safeguard existing achievements with greater effect. All the stakeholders potentially have much to offer.

Getting Started: Bringing it Together

The debate which commenced in the Disability Research discussion group is not new. This issue of *DSQ* brings parts of the debate again to our attention. We need to continue the debate in more widespread and accessible venues, opening the discussion to all the relevant stakeholders, if people with disabilities want to see improvement of their situation. It is not enough to reiterate arguments based solely on our own personal contexts. Going to the core of what various individuals believe and assume about their position in society will allow us to confront the tensions within personal, cultural, social, and political contexts. What an open and honest conference can achieve, and what ongoing, localized efforts can further, is a clearer focus on the experiences of various stakeholder groups, a better idea of for whom they speak, and greater insight on the specific nature of the interrelating barriers and conflicts of interests that presently appear to divide our efforts.

In trying to achieve this clarity, I suggest the following discussion points:

1. Who sets the disability movement/advocacy agenda?
2. Whose benefit does that agenda serve?
3. Who are the stakeholders and what relationships exist between them?
4. What are their beliefs and assumptions about the nature and purposes of disability

concepts, about the experiences of disability, about the world, about people?

With these questions out of the way, I suggest that there be concentrated attention to four further points:

1. The identification and explication of current approaches to disability.
2. An assessment of the values and pitfalls of those different approaches and the relationships between them.

3. If we are all saying we are acting in the interest of furthering the cause(s) of people with disabilities, how can we productively use and organize our diverse roles, approaches, and theories and minimize any potential negative outcomes to people with disabilities?

4. How do we keep directly in touch with disability issues on the ground and how do we best use academic work in support of grassroots change?

In sum, I am not suggesting that we could, or even should, be one big, happy family with completely common aims. Tensions, after all, are not all negative; some are necessary for growth. The different stakeholders do have some genuinely different interests. Let us lay them on the table and collectively strive for greater depths of understanding. That in itself would be a great strength with real potential benefits for citizens with disabilities.

We do all have an obligation to build bridges between various groups, walk across, gain understanding and clarity, and walk back again with a greater understanding and respect while leaving the bridge intact so others can visit us. This may pave the way to greater advances in meeting the needs and interests of people who have disabilities. Paradoxically, this would be a kind of dynamic and united front in diversity. In this way various stakeholders may come together around fundamental values and insights, rather than primarily around stakeholder labels, forming coherent and potent forces for advances in the position of people who have disabilities.

I think it is well and good if an international conference along these lines ever comes about. I would try to get there too! But perhaps, more realistically and appropriately, we need to

understand that since not every disabled person or ally is able to get to an international conference there are many things we can do from our own locales via the conventions of face-to-face dialogue and Internet discussion groups. If the necessary bridges are going to be built, we must take a respectful and open approach.

NOTE: In Australia the term "people with disabilities" is the preferred way to address "us," placing the emphasis on the person rather than the condition. I know this is not always the usual terminology in other countries and sometimes seems unwieldy; but since I write from an Australian context, I use it here.

References

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