

# Crip Culture and Clinical Trials: The Disability Movement *versus* (Exclusionary) Standard Practice.

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**S**trange Notions. *Crip culture?*<sup>1</sup> *Disability Pride?*<sup>2</sup> If you know those terms, you are in a small minority. If you don't know them, you may have flinched on first hearing such strange notions, perhaps embarrassed that they seem to make light of what you believe is the tragic essence of disability.

Yet, the strange notions may intrigue you...

Add to the mix similar terms, such as "*Disability Cool*" and "*Disability Chic*," and labels for non-disabled people, including "*TABs*" (Temporarily Able-Bodied). All are terms of choice by activists in a burgeoning social movement to re-engineer the negative social consequences long associated with medically-defined "impairments."<sup>3,4</sup>

Social Movements. In the 1960s and '70s, similar slogans seemed equally strange: "*Black is Beautiful*." or "*Sisterhood is Powerful*." Those slogans flowered after the social movements around minority racial identity and women's gender identity had each begun to flourish. The slogans by now seem bland, but originally marked a major shift in each movement: *from* negatively-framed aims -- eliminating oppression and claiming civil rights -- *to* a more encompassing aim, framed around the group's positive sense of identity. Audaciously, those social movements came to celebrate the very characteristic that had been stigmatized. No longer satisfied to be just "tolerated," Blacks and women sought full inclusion, offering thereby to enrich the cultural lives of their communities and the nation.

Why bring that up here? If we are to discuss the reasons and ways that people with disabilities are underrepresented in clinical trials, we must convey the similar social movement nature of the issues. This is more than using analogy; it acknowledges historical links from the earlier civil rights movements to the Disability Movement of today. In addition, the social movements of the past are intricately linked with

the Disability Movement today, as captured by the jargon-y term "intersectionality." People with disabilities also are influenced by their gender, age, ethnicity, sexual preference, religious, social class, and other culturally-relevant identities.

By definition, when a movement is underway, some people have adopted a new mindset, and others haven't, yet. Many people have not even heard of the Disability Movement, or if aware, they probably think of its early focus on gaining access to basic civil rights, such as voting, employment, and use of public facilities. The later phase -- celebrating disability identity through creative cultural expression -- is beyond the ken for most of the general public, including most people with disabilities. Most have never questioned the old mindset about disability.

Mindsets, Old and New. What are the old and new mindsets about disability? Concisely, they are the "medical model" contrasted with the "social model." The **medical model** explains the *social* consequences of impairments by the nature of the impairments, e.g., deafness or paraplegia or blindness is considered sufficient explanation for being excluded from work opportunities, or from using buses, or from knowing about recruitment notices for clinical trials in newspapers.. The **social model** sees exclusion as a societal phenomenon, and shows that inclusion happens *if* society chooses to design the environment to allow access by the different ways people with impairments get around (e.g., by using crutches or wheelchairs), or gather information (e.g., by using captioning on TV or audio access to print notices).

To clarify: Rejecting the medical model does *not* mean rejecting the idea that there are *medical* causes and consequences of impairments, which are appropriately addressed by clinical care and clinical research. It *does* mean rejecting the idea that medical causes explain *social* consequences, which are appropriately addressed by anti-discrimination laws, and by training architects, civil engineers, publishers, clinical researchers, and so on, in the many high-tech, low-tech and no-tech ways to assure access to the built environment and to information

Against that background, what are specific barriers to participation of people with disabilities in clinical trials (CTs)?

Physical/Informational Access Barriers. Probably most exclusion from CTs is inadvertent, reflecting barriers built into our taken-for-granted ways of doing things that often fail to accommodate people with impairments. Every stage of CTs may be affected, starting with *recruitment* notices that cannot be seen (excluding people with visual impairment or blindness) or read (cognitive impairment) or heard (hearing impairment, deafness), to *eligibility screening* by phone (eliminating those with hearing or speech impairment), to conducting *intake* and *study procedures* on equipment unusable by people with certain orthopedic or neurological impairments. In addition, such barriers often keep people from accessing needed health care<sup>5</sup>, which not only has serious direct effects, but also is an indirect barrier to CTs, since under-utilizers of health care are less likely to be informed of CTs by practitioners.

Sometimes researchers become aware of such barriers, but they lack either the knowledge or motivation to provide accessible alternatives. Researchers may also worry about costs, not having budgeted for such contingencies (although government funding agencies are receptive to such budget items, in line with the accessibility mandate of the 1990 “Americans with Disabilities Act”). Due to a limited understanding of accessibility techniques, researchers are unlikely to know what such costs -- if any -- really are.

Attitudinal barriers. A case could be made that “attitudinal barriers” should have been listed first, if we include not only expressed prejudices against dealing with people with various impairments, but also “institutionalized ableism” – i.e., exclusionary attitudes that are subliminal, accepted *via* the taken-for-granted built-in barriers discussed in the prior section.

In terms of expressed attitudes, the problem usually doesn’t take the form of a researcher (or practitioner or technician involved in recruiting) excluding someone because he/she “dislikes” working with people who have impairments, although that may occur. More likely, the expressed attitude is “discomfort” in dealing with people with speech impairments or poor motor coordination (e.g., cerebral palsy); that attitude may be projected and rationalized as “saving” the disabled person from discomfort (a subtle form of “blaming the victim,” since the researcher justifies a patient’s exclusion seemingly by reference to the patient’s discomfort, but ultimately, the reference is to his or her impairment.).

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The answer to this difficult problem (similar to dealing with “institutionalized able-ism”) is simply that we have to start somewhere in a trust-building enterprise, and not expect overnight results. Researchers must collaborate with community leaders among persons with

disabilities to learn the best approaches to gaining not only their individual involvement in research but also their guidance for involving others.

Clustering of Factors. Finally, we return to that handy word: “intersectionality.” One aspect of intersectionality is that disadvantaged social statuses tend to cluster. Although all social groups experience impairments, it is true that disability is associated with poverty and each contributes to underrepresentation in CTs. Furthermore, disability rates are higher in rural than urbanized areas, among elderly persons compared to younger adults and/or children, and among disadvantaged ethnic minorities compared to the dominant groups. Each of those related factors has been found to operate in its own right as a source of underrepresentation in CTs.

However, it is the combined effects of multiple statuses in real-life situations that must be addressed. To understand better how standard practices in CTs heighten or minimize barriers to participation, depending on the mix of social characteristics participants bring to situations, we need to hear about these experiences in the words of those who face these challenges. Hence, qualitative research holds great promise.

Moving Ahead. At first blush, the “promise” of in-depth qualitative research might seem to require an unacceptably long-range approach to dealing with a problem that is here and now. Yes, it could take vast inputs of money and especially time to carry out qualitative studies that adequately represent the diversity of CT situations, multiplied by varied patterns of participants’ social statuses. But that discouraging prospect overlooks that much of the needed information is almost at hand, waiting to be culled from the combined experiences of (a) persons with disabilities who are experts about barriers in settings common to CTs and (b) clinical researchers who are experts about the requirements and resources for conducting CTs.

There are two efficient ways to access that fund of double-edged expertise: One approach intended to acquire a comprehensive understanding of the situation is to generate discussion (whether in person, by phone, or in cyberspace) between groups of non-disabled researchers and *key informants* - people with disabilities who have experienced and thought about barriers in health settings. As informants about disability culture, national activists actually engaged in building “Crip Culture” or “Disability Pride,” etc., will surface early. They then can identify broader networks for wider and more heterogeneous coverage. Scholars in the emerging field of Disability Studies, (see the Society for Disability Studies<sup>6</sup>), might facilitate such a search as well as offering their own expertise.

The second way to fruitfully plumb the relevant expertise is to interview people who, within themselves, combine the clinical researcher and disability experience. That is still a small cadre, but growing as educational and occupational barriers ever-so-slowly diminish. Several federal research funding agencies can help identify such dually-qualified informants.<sup>7</sup>

Conclusion: Who benefits? What if standard practices of CTs *are* effectively modified to allow broader inclusion of people with disabilities? Who would benefit? Here the question is not posed in familiar terms of individual risk/benefit, as is central to the informed consent process. Rather, the question refers, uncommonly, to the collective level, meaning benefits (or risks) to clinical trials “generically,” compared to benefits or risks to “Crip Culture.” Being a novel query, and in view of limited space, the question can be approached only speculatively and minimally. Still, the exercise may be revealing.

CTs would benefit mainly by having larger pools for recruitment. Also, if making “reasonable accommodations” works as it has in other situations, environmental modifications that are *necessary* to include people with long-term impairments will also *facilitate* participation of other people, either with temporary impairments or for whom accommodations are a convenience. Furthermore, building a reputation of inclusiveness around disability should improve willingness to participate among other groups with histories as targets of discrimination.

*What are the risks?* Perhaps the most obvious “risk” would be the possible added dollar costs for accommodations. However, the bulk of the cost is incurred when accommodations are developed and are then minimized the more that the accommodations are in use.

Now, what about benefit to “Crip Culture” – or more broadly, to the Disability Social Movement? Remember, this question doesn’t refer to individuals, but to the collective. I speculate that greater participation in the work of the health sector by disability activists would start repairing the major remaining thin spot in the fabric of community life that the movement has not fully addressed. Throughout the early years of the Disability Movement, problems in the health sector were largely by-passed. That decision was understandable as a reaction to public and professional tendencies to attribute *all* disability-related social barriers to individuals’ medical conditions. Activists needed to convey the unrecognized breadth and depth of civil rights violations in virtually every other sector: education, employment, voting, recreation, transportation, and so on.

But now that the movement is entering its “mature” phase, with Disability Pride ascending, it is time for the pendulum to settle in a position that puts health-related activism on par with

disability activism in all other domains. From there it shouldn’t be long before Crip Culture and Clinical Trials will no longer seem strange notions appearing in the same sentence.

## ENDNOTES

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<sup>1</sup>The 1995 (also attributed as 1997) video, *Vital Signs: Crip Culture Talks Back*, recounts the early days of an affirmative political and artistic culture based on shared aspects of the disability experience. An annotation of it is at <http://litmed.med.nyu.edu/Annotation?action=view&annid=10094>

<sup>2</sup> For an example of the philosophy behind this concept, and some activities expressing it, visit [www.disabledandproud.com](http://www.disabledandproud.com).

<sup>3</sup> For an analysis of historical changes in the terminology associated with disability in the United States, see Ben-Moshe, L. and Kirchner, C. “Language and Terminology,” entry in the forthcoming *Encyclopedia of American Disability History*.

<sup>4</sup> For an analytic set of concepts and terms (e.g., “impairment”) gaining global use, see the World Health Organization’s *International Classification of Functioning, Disability and Health*, at [www.who.int/classifications/icf/en/](http://www.who.int/classifications/icf/en/)

<sup>5</sup> Iezzoni, L I, and O’Day, B, (2006) *More than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities*, New York: Oxford University Press.

<sup>6</sup> [www.disstudies.org](http://www.disstudies.org) is the website of the Society for Disability Studies.

<sup>7</sup> The National Science Foundation, which has an initiative devoted to broadening participation of underrepresented groups in scientific research; the National Institutes of Health; the Office of Disability and Health in the Centers for Disease Control; the Office of Disability in the Department of Health and Human Services; the National Institute on Disability and Rehabilitation Research in the Department of Education; and the Office of Research and Development in the Veterans Health Administration.