Making Room for Difference

An Anarchist Response to Disability

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I won't name the city or the group–it isn't necessary. Similar situations have occurred in every anarchist community. A middle-aged man with obvious mental health difficulties attached himself to an anarchist activist project in a major city. He had time and energy to spare. He also had difficulties managing his behavior sometimes. A group of young women thought his occasionally aggressive words and actions were threatening, and they were lobbying for his expulsion from the collective. Others grumbled that his personal hygiene was lacking, and that his presence drove away potential members.

As a visitor to the project, I don't know how this story ended. I do know that no one seemed to be grasping the need for social support that had attracted him to the group, or the internalized unease that contact with someone who was experiencing mental illness provoked amongst people who believed themselves to be sympathetic with "diversity" as a broad concept.

It's a problem that I have wrestled with on a personal level, as the parent of a child with autism. When my partner and I were in greatest need of support and practical help, we did not find it within the anarchist community. As we couldn't cope on our own, we had to turn to the school and healthcare systems: in other words, to government and business. As our son reaches adulthood, his future appears likely to require ongoing assistance from the government. This is hard to reconcile with our politics. It requires making compromises with systems that are often arbitrary and coercive. It's also scary, because government services under neoliberalism are anything but reliable. We have founded support and advocacy groups, but these, too, necessarily become heavily involved in lobbying government agencies for special education services, income support, medical care, and official recognition of the human rights of people with disabilities.

This is not the fault of modern capitalism alone. There is no enlightened era of past practice to which we can return, no shining example of current communities that do much better. As a researcher of disability history, I can say definitively that societies that even attempted to provide quality care for individuals with disabilities have been the anomaly, not the rule. Foucault's happy pre-Enlightenment "ship of fools" was a fantasy: the reality of life with disability (particularly developmental disability and mental ill health) before charitable/government involvement ranged from outright murder, to banishment into charitable and religious institutions, to imposing the full duty of care on women within the confines of the family home. All of these practices continue alongside government and corporate services today.

We can't look to our anarchist past for answers, either. As Richard Cleminson documents, many anarchists have been believers in eugenics, including involuntary or "voluntary" sterilization of the "unfit". Charles Hawtrey notes that during the Spanish Civil War, injured anarchists were returned to their families (for which, read: the women in their families) post-triage, not to cooperative community care.

And although capitalism contributes to workplace accidents, poor attention to the health and safety needs of non-elites, and stress, means disability will not be magicked away in a revolutionary moment. In addition, providing appropriate care for many forms of disability requires expert medical assistance, and experts have a tendency to constitute themselves into powerful elites that can challenge non-hierarchical organisations. Human difference and its social consequences are not something we can ignore.

Imagining a different approach

To conceive of an anti-authoritarian approach to disability, it helps to start by rethinking the way we think of disability itself. The concept used by most disabled peoples' organisations is the social model of disability. This radical notion holds that disability is a social product. The human body and mind are infinitely diverse, and change throughout life as a result of experiences, accidents, aging and so on. The differences in ability that result are normal, not abnormalities to be excised. What turns differences into disabilities is the construction of physical and social barriers that prevent people with certain kinds of differences from functioning. An obvious example of this process would be building doorways too narrow for wheelchair users; a less obvious one would be expecting everyone at a meeting to have the same level of intellectual ability. The barriers societies create act to produce disabled people, in the same way that other sets of social relations produce hierarchies of race and gender. Disablement, in other words, is a process of discrimination and oppression, not an individual or family problem.

And if disability is a social product, it should be clear that addressing it is also a social issue–not a matter for governments, nor the sole responsibility of families, partners and friends.

Thinking of disability as a social product doesn't mean ignoring the impact of illness, pain, and impairment. Not addressing these issues properly is one of the biggest barriers to be overcome. Figuring out exactly how highquality medical care and innovation might be managed in an anarchist society is not easy. Some parts seem obvious, like ensuring that people have the tools and information they need for self-care when that's possible, and that individuals and communities take steps to prevent unnecessary injuries. More complicated help could be available in community settings where healthcare workers and those in need of their services work cooperatively–here, we can learn much from past and current feminist and radical health collectives. Handling things like brain surgery, complex orthopedic repair, and drug research takes a lot of resources, however, from sterile operating suites to many years of education and practice. If it was you on the table, you wouldn't want to see a newly trained volunteer in charge! Finding ways to prevent expertise from translating into elitism and power hierarchies is a real challenge. Having the wisdom to know the difference between a health problem that requires medical help and a difference that requires social support and accommodation is also hugely difficult.

There are current practices that fit into non-hierarchical frameworks. One of these is the self-help movement, as exemplified by the Independent Living movement (www.independentliving.org), the Icarus Project (www.theicarusproject.net), the feminist women's health care movement, and even some addiction recovery groups. However, many self-help groups rapidly find that more time is spent on lobbying for government funding and policy change, fundraising, or writing grants, than on caring for each other directly. The reality is that in capitalist societies time, services and equipment cost money. Self-help groups can also be isolating, encouraging people to see their "disability identity" as their total identity.

Authoritarianism can also emerge in new guises. Many past experiments in "radical psychiatry" have devolved into therapy cults, with guru-like figures causing untold damage to people in need of help, or using them to meet their own ego needs. "Social Therapy," which spawned the New Alliance Party, and Re-evaluation Counseling (co-counseling) are just two well-known examples.

We tend to import other mainstream concepts into "radical" contexts as well. We may assume that individuals who are unable to care for themselves or who make few or no material contributions to their community are less valuable than others.

We may think it's only natural that families, lovers, and friends should be someone's carers, not us. We may feel outside of our comfort zone when confronted with the messy realities of disabled people's lives, whether that's the need for assistance with toileting or the confusion and anger that people may feel as a result of either their condition or their social exclusion.

One promising approach is called "circles of support." < http://www.circlesnetwork.org.uk/home.asp?slevel=0z&parent_id=1 > These are groups of people who make a voluntary commitment to a person with a disability. This commitment

can be for just a period of time, or for life. The person with a disability is the focus of the circle, and all members work together to ensure that the person is included in social activities they are interested in, and to brainstorm solutions to problems that have become disabling barriers. Circles of support have come together around people with physical disability, mental ill health, and intellectual disabilities. They act as friends, a relationship with fewer power differentials than that of service user/paid carer or disabled person/family member.

Incidentally, this approach has also been used, with great success, to support sex offenders released from prison so that their communities can be safe from further abuse.

Which brings my thoughts back to the man I described at the beginning of this article. What he sought by becoming involved in activism was not very different to what I have often been looking for. Sure, I wanted to change the world, but that desire is rooted in experiences of joy and personal power experienced in collective action, which I wanted to have more of, and in experiences of exclusion and pain that I wanted less of. We both wanted connection to others, to ensure that our needs are met, and to feel needed by others. He may have needed some help in managing his health, and our community did not seem to be providing that. He certainly needed help in successfully being part of the community, and a circle of support might have been a good approach to meeting both his needs and those of others to feel safe.

From seeing disability to supporting disabled people

Since people with disabilities are so segregated from mainstream society, it's easy to ignore their presence unless it touches our lives directly. Of course, eventually it will do so: most of the people reading this article will grow old, experience serious illness, or suffer an injury. Many will become parents, and current statistics indicate that 1 in 12 children in the U.S. has a disability of some kind; and as Z. Uyangaa notes, the rate is twice as high in the developing world.

These statistics shouldn't surprise you. In the West, we hide disability in special schools, hospitals and nursing homes. In the rest of the world, it's often hidden at home, or results in early death. These approaches allow people to avoid a direct, personal experience of disability, and to see it as an abstract issue. We rarely confront our own complicity in the social exclusion of disabled people.

Challenging disablist attitudes starts at home, within our communities and projects. Are there disabled people who visit your infoshop, social centre, collective cafe, or group meetings? Find out if they are experiencing any barriers to access or social inclusion. Often only small steps are required. For example, Marisa Sposaro, a blind anarchist in Australia, was supported by her comrades, who have had bulletins and literature put into Braille, and who had Braille labels made for the cash register at the collective grocery so she could help out there.

As Sandra Jeppeson writes: "People have the right to health, and we must ensure that as a community we support this right without making each other feel that we are needy or demanding; rather each person's needs are paramount, and each person has the right to define their own needs and have those needs met."

We have to find ways to provide the human services we require, a process that begins with accepting and valuing difference, proceeds through entering direct and equal relationships with disabled people, and will hopefully culminate in finding ways to provide the support, care and services needed outside of hierarchical, profit-driven systems, always involving encroachment, and so its intrusion should be made into a visible development. Third, we need to create an outline of the community practices which have been damaged by the introduction of mass media forms, from newspapers to radio to the Internet. Then a graduated plan to address and roll back the systematic alienations introduced by each of the media through history should be initiated.

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