

# **Power to Independence: A Historical Glimpse at the Interactions between Powered Wheelchairs and the Physically Disabled Students Program at Berkeley.**

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## **Abstract:**

The emergence of powered wheelchairs has revolutionised the experience of disabled people. Not only have they enabled individual independence, but as we will argue, they were also central to the development of the disabled people's movement. However, we do not present a technological determinist position, certain social and political conditions needed first to be in place before powered wheelchairs became meaningful. In this paper, we will present a historical analysis of an example where powered wheelchairs both shaped and were shaped by the Disability Rights movement: The Physically Disabled Students Programme (PDSP). In the United States, in the early 1960's a small number of disabled students gained admission to the University of California at Berkeley and laid the foundation for the PDSP. Graduates from this programme went on to found the Independent Living Movement, which influenced not only disability politics in both the US and Europe but also challenged established ideas about wheelchair design and use.

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For most of the 20<sup>th</sup> century, wheelchairs have had an ambiguous status. In one respect, the inextricable ties between wheelchairs and injury or illness has resulted in the rise of their dominant meaning as medical device: as machines that doctors prescribed only to the sick or the wounded. Yet, in another respect, the medical profession, especially rehabilitation professionals, have, at least historically, interpreted wheelchair use is a sign of failure – both for them, in that they did not find a cure for the particular impairment – and for user, in that it signalled an inclination on their part to give up on being rehabilitated. In yet another respect, wheelchairs have had no status at all. At the cutting-edge of science and technology, wheelchair research attracts little kudos and to the majority of medical professions wheelchairs are nothing but insipid technologies unworthy of serious attention. This lack of status or recognition also extends beyond the medical sphere into the built environment, where the definition of wheelchairs as medical device and their detachment from the everyday experiences of the majority, has led to the neglect of public transport systems to build-in the wheelchair and the failure of architecture and town planning to account for wheelchair use.

The reasons that underlay this ambiguity are found, at least in part, in the definition of disability as a problem of medicine, rather than as a problem of discrimination, and in the ideology of normalization, which has long been an imperative of rehabilitation. This notion of normalcy with its strong association with the medical-industrial construction of disability formed the central goal of rehabilitation: to reconstruct and reintegrate disabled people into the industrial body. With its concentration on cure or alleviation of impairment, the traditional technologies of rehabilitation have been the prosthesis, the calliper or the brace – the

material forms of the idea that you could replace what was ‘lost’ – that rehabilitation could return disabled people to some prior situation, even if that prior situation never existed. This normative framework reinforced the separation of wheelchairs from the mainstream and underpinned the notion that their use was abnormal (Finkelstein 1984; Moser 2000; Oliver 1996; Stiker 1999).

The ambiguity of wheelchairs however, is more complex. Wheelchairs have multiple meanings attached to them simultaneously. Within this paper, we look back to a moment in history where disabled people challenged the medical hegemony and in so doing, reinterpreted the meaning of wheelchairs, and reclaimed them as tools of independence and as political instruments. The moment is the famed emergence of the Physically Disabled Student’s Program (PDSP) in Berkeley, California, but the aspect we intend to explore, the interactions between powered wheelchairs and the beginnings of the independent living movement, is less familiar. When the founders of the PDSP developed their concept of independent living, it was apparent to them that along with financial benefits advice, advocacy, and a system of attendants, the PDSP had to provide a wheelchair supply and repair service, for without it they would not realize their goals (Collignon 1998; O’Hara 1997; Pachovas 1998; Perotti 1998; Zukas 1997).

The impact of powered wheelchairs and the independent mobility that they afforded was a powerful experience for many attending Berkeley. As Suzanne O’Hara, Director of the Berkeley Disabled Students' Program from 1988-1992, recalled:

The upshot of it was I came out to spend the summer, the summer of '71, and they [the PDSP] lent me a [powered] chair, which seemed like a miracle at the time, ... it was one of the most revolutionary experiences of my life. ... To go from being pushed ... to being able to control where I was going and the person with me was in a strictly social role, I found that exhilarating. ... It kind-of opened up a whole world of being able to live on my own (O'Hara 2002).

Ed Roberts, one of the founders of the PDSP, described the impact of his powered wheelchair in a similar vein:

I was always in a push chair. I was in a recliner, push chair. It was frustrating sometimes, but in one way, it was nice to have people with me all the time. In another way, whenever we went to a museum or a place that I wanted to look, I had to stop them. And the other thing that I noticed heavily was that when people would walk up to me, they would talk to my attendant. I was almost a nonentity, being pushed around. After I got my power chair, I realized that they had to confront me. All of a sudden, there was no one else there. That was very important for me to realize that (Roberts 1994).

As Roberts alludes, powered wheelchairs not only enabled newfound independence for their users, they were also part of the engenderment of their politicisation. In Berkeley, the first incarnate of this politicisation's came in the form of the Rolling Quads: a group of radical disabled students who had gained admission to the University of California at Berkeley in the 1960s. Dissatisfied with the services provided by the California State Department of Vocational Rehabilitation (DVR) and their lack of control over them, the Rolling Quads responded with direct action. As Gerald Belchick, Department of Rehabilitation Counselor and Liaison to the Cowell Program in the 1970s, recalled, these early protests also highlighted the potency of wheelchairs as a political symbol:

All the activists in Berkeley had a half a dozen causes to rally around, and this was a very visible cause. It was everything – it would be an organizer's dream – because you didn't have to depend on rhetoric; you could just depend on

what you could show. And, of course, this panorama of all [of] them in wheelchairs. ... But anyway, it made all the papers, and it made it in grand style. The department was embarrassed (Belchick 1998).

The demonstration, although only small in number, was symbolic. It only took a small number of wheelchair users to jolt the DVR into action and it was also is a very powerful experience in terms of making the participants aware of their own political strength (O'Hara 2002). The Rolling Quads gained a student advisory committee with the DVR, which enabled them to gain some control over issues effecting disabled Berkeley students resident at Cowell. However, some members of the Rolling Quads began to examine the possibility of establishing a student service programme independent of the DVR and mobilized to elicit resources from TRIO Programs, a fund established under the Economic Opportunity Act 1964 and reauthorized under the Higher Education Act 1965, which provided financial aid to 'disadvantaged' students. Success in this endeavour led to the emergence of the Physically Disabled Student's Program (PDSP), the central plank of which was that disabled people controlled the organisation, and thus its policies (Grimes 2003). Before this, non-disabled 'experts' ran services for disabled students. This change set the tone for the most important and radical component of the PDSP: that those who best know the needs of disabled people and how to meet those needs are disabled people themselves.

Powered wheelchairs were not only central to the founding of the PDSP they were also essential to its everyday management. Indeed, it is doubtful whether such a programme would have been possible without this technology. However, whilst powered wheelchairs afforded the realization of political empowerment and the possibility of independent living, the unreliability of the technology hindered its attainment. O'Hara (1997) noted how her "wheelchair was in the repair shop about

every other day” and research conducted on behalf of the PDSP found that the powered wheelchairs used by Berkeley students were so unreliable they required, on average, \$900 (\$2,133 in 2000 US dollars) worth of maintenance per year (Medsger 1979).

One form of powered wheelchair commonly recalled was the Motorette, a self-contained, strap-on, power unit, produced by the Motorette Corporation that when attached to a manual wheelchair, sat on top of the rear wheels and drove them via a small cog that pressed against the rear tyre. As with most powered wheelchairs of the period the Motorette was not free of problems. The drive mechanism would not work properly if the tyres were under-inflated or wet. The weight of the motors on the rear made the wheelchair unstable, which often resulted in it tipping backwards and at ‘high-speed’ they often blew a transistor, which on occasion threw the occupant from the chair; leading to them earn the soubriquets, “bucking bronco,” or “murderette” (Krizack 2000; Roberts 1994; Willsmore 1994; Pachovas, 1998).

The problem of poor technology thus had to be overcome if the students were to achieve their desired aim of independent living and the students had to explore various avenues on how best to achieve this (Perotti 1998). When John Hassler, Ed Roberts and others, first set up the PDSP they quickly became aware that the provision and repair of wheelchairs would be a primary requirement for its success (O’Hara 1997). Initially, the PDSP placed its wheelchair repair service in the hands of a local wheelchair supplier, Robin Aids. However, it was apparent that this service could not fully meet the needs of the wheelchair users. Hence, attendants, in particular Chuck Grimes started to carry out minor repairs, such as the replacement of fuses,

repairing tyres and so on. This ad hoc repair work eventually led to the setting up of a wheelchair repair service, which became an integral part of the PDSP and one of the three central elements of the programme (Grimes 1998 and 2002). The resulting wheelchair repair service was much more able to meet the needs of the users. As Suzanne O'Hara recalled:

If your chair needed to be fixed, they understood that you didn't just shut down your life at five p.m. The thinking was, "What does the consumer need?" It was fantastic. You could have your chair repaired on the spot instead of the standard waiting three weeks, which you had to do any other place in the country (O'Hara 1997).

The wheelchair technologists, as they became known, eventually moved beyond simple repair work to become involved in innovation projects: to start to change the way the technology worked. At this time, there was a general feeling of distrust of the wheelchair industry. Many users considered that wheelchair manufacturers did not listen to them or take their complaints seriously. Wheelchair users knew all the faults, and did on occasion report these faults to the manufacturers, but they saw little evidence of manufacturers acting to improve wheelchair design (Grimes 2002).

The successful acquisition of an Innovation and Expansion grant to design a new powered wheelchair led the way for a challenge to the dominance of the wheelchair manufacturers. By drawing on both the expertise of the users and their own engineering experience and knowledge, the wheelchair technologists began to address the key problems with powered wheelchair design (Ibid; Grimes 1998; Leon 1998). Although advertising painted a picture of 'all-purpose' powered wheelchairs, for use both indoors and out, in actuality most manufacturers had designed their

products for indoor use only (Everest & Jennings 1961; Motorette 1972). As such, student at Berkeley were operating their technology beyond the design limits. This experience meant that both wheelchair users and wheelchair technologists knew the key design problems and they attempted to evolve a system that would give the chairs a longer range and make them go faster (Grimes 1998; Leon 1998).

The work and ideas stemming from the PDPS wheelchair repair division went beyond the boundaries of Berkeley. Not only did it influence the establishment of similar types of services within the emerging independent living movement, which aimed to provide similar services to disabled people who were not students, it also inspired many others not to simply accept the technology available, but to begin actively change it. The spark for this movement was probably the Wheelchair Technology Conference of 1978. Hosted by the Federal Rehabilitation Services Administration, the conference was attended not only by rehabilitation professionals by also by representatives of the PDSP, the Center for Independent Living (CIL), the Veterans Administration (VA), the National Aeronautic and Space Administration, the National Institutes of Health along with representatives from industry, academe and from other organisations of and for disabled people. It was an important moment in the history of powered wheelchairs because it was the first time that all of the different constituents involved in wheelchair design and use got together. For users, it provided a space where they could inform wheelchair designers of their experiences with and expectations of the technology, as Wheelchair Technologist, Chuck Grimes, recalled:

Our pointed social-political goal was to bring an awareness that these are real grownups living real lives, and you can't have these kind of baby carriages



with little electric toy motors strapped to them and expect to have that to support an independent adult going about their life (Grimes 1998).

In some measure the realization of this socio-political goal came when both the VA and the Office of Science and Technology Assessment, finally recognized that there was a need for a high-performance, purpose-built, indoor/outdoor powered wheelchair (Lipskin 1974; Shepard & Karen 1984). Research conducted by the VA Prosthetics Research Center in the mid to late 1970s demonstrated not only that new types of powered wheelchairs were technologically possible, but also that there was a growing market for them. In this respect, those who worked at the PDSP and then later the Centre for Independent Living, were agents of both social and *technological change*. Not only did they inspire a movement that redefined the meaning of disabled people's independence and demonstrated its possibility, they furthered a material, political and an ideological reinterpretation of powered wheelchairs.

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