THE PROSPECTS FOR UNIVERSAL DISABILITY LAW AND SOCIAL POLICY

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Abstract: The worldwide disarray of disability social policy and law requires a new foundation to make it coherent and to remedy persistent contradictions, disincentives and other policy anomalies. In this paper we clarify and expand Irving Zola's call for 'universalized disability policy' and develop his insight by drawing upon the well-known principles of Universal Design (UD), or Design for All, in architecture, product development and city planning to formulate analogous principles of universally designed disability social policy and law. Our objective is to show, by means of two examples - one in health care delivery and the other in welfare or social support policy - that 'universalized' policy for and on behalf of persons with disabilities is feasible. We find that there are some, albeit limited, examples of universalizing policy in these areas and suggests ways in which the full range of UD principles might be able to be implemented in these two policy areas. What we propose is merely a proof of concept rather than a complete proposal to restructure disability law and policy - which likely not be feasible, given the range of social and economic conditions of countries around the globe. We conclude with some tentative suggestions for areas of empirical research that would further the overall agenda of a universal disability social policy.

Keywords: universal design, disability policy, disability law, minority group approach, welfare.

Introduction

Social policy and law for, and on behalf of persons with mental and physical disabilities is in disarray, worldwide. In part, this is a result of the extraordinary diversity of disability policy and law. In most developed countries, besides basic human rights or anti-discrimination law, one can find relevant pockets of policy and law addressing disability issues in medical and rehabilitative services, long-term services and supports for individuals and families, institutional care, independent living, income security, health and safety legislation, compensatory accident and unemployment schemes, as well as policy regarding employment, education, housing, communication, transportation, assistive technology, data collection and research. This is an enormous array of programs and it is understandable that coordination would be an endemic problem. But the disarray has deeper roots (see Bickenbach, 2011).

There is a persistent gap between expectation of the objectives of policy and law and the actions taken to implement them. There is also a lack of consistency and coordination that results in ad hoc and 'add on' social programming and a generally reactive legal response to disability issues (Stone 1984; Bickenbach 1993). Disability policy is rife with disincentives, lack of accountability and an apparent lack of political will to put policy and law on a firmer footing. In developed and developing countries alike and in every area of law and policy there are glaring anomalies and inconsistencies; there is also a dilution of purpose and ambiguity of aim.

This has been known for some time, and a variety of explanations have been offered. Most of these explanations point to a lack of understanding of what disability is (and what it is not). A consensus has developed that disability is a complex phenomenon, at least in part socially constructed, and in any event not in any straightforward sense a discrete attribute of a person. Disability, most researchers now agree, is a collection of outcomes of social and other environmental interactions with mental and physical health conditions (WHO, 2001). We might call this the 'new paradigm' of disability, or even the received view of disability: this approach has been adopted in the United Nations

Convention on the Rights of Persons with Disabilities (UN, 2006: Preface; and see Leonardi et al., 2006).

But if there is consensus about the concept of disability in the social sciences and disability studies, there is far less agreement in disability law and social policy. In these domains, internal debates about conceptual approaches to disability are more entrenched. Moreover, the only likely candidate for a common language of disability in social policy and law is that provided by economics, which is no reason to be optimistic: economic theory insists that disability is a social cost that must be minimized in order to achieve cost-effectiveness, a view opposed, not only to the new paradigm of disability and its underlying human rights perspective, but also to the political aspirations of persons with disabilities for social equality and full participation.

In this paper we begin by clarifying an insight first suggested by Irving Zola's called 'universalized disability policy' (Zola 1989). We propose to develop Zola's insight by drawing upon the well-known principles of Universal Design (UD) in architecture and planning in order to formulate analogous principles of universally designed disability social policy and law. We will develop policy and legal analogues of the UD principles and sketch out two examples of universal law and social policy. Our primary objective is to show, by means of these examples, the feasibility of universal policy and law. We conclude with some tentative suggestions for areas of empirical research that would further the overall agenda of a universal disability social policy.

The idea of Universal Design

According to an early characterization by Ronald L. Mace, UD means, "designing all products, buildings and exterior spaces to be usable by all people to the greatest extent possible." (Mace et al. 1991: 195) Designing products and environments (tools, homes, and entire cities) for maximum usefulness requires taking into consideration the full range of capacities that people have. UD, in other words, "respects human diversity and promotes inclusion of all people in all activities of life" (Story et al. 1998).

Universal design promotes integration across the range of human life, and potentially for every area of life in which people participate. Designers are advised to design for all people, and to do so must acknowledge disability, the manifestations of aging and other differences that constitute the range of human variability. Human beings have diverse repertoires of abilities; so while it is true that we are living longer and surviving injuries and illnesses, UD is not a response to some new demographic trend. It is a realization of the range of human normality that has always been with us.

Most commentators are quick to point out that UD is very different, in spirit and consequences from another general principle of design easily confused with it, namely barrier-free or accessible design. Barrier-free design originated in the 1950s as a response to demands by disabled veterans and advocates for people with disabilities to create opportunities in education and employment rather than relying on institutionalized health care and maintenance. In particular, physical barriers were recognized as a significant hindrance to people with sensory and mobility impairments in all areas of their lives. In the U.S., national standards for barrier-free buildings were proposed in 1961 by the American Standards Association (later known as The American National Standards Institute), which published the accessibility standards which, through the offices of the International Organization for Standardization, have been adopted internationally (see, ANSI, http://webstore.ansi.org/default.aspx).

Like the so-called "special needs" approach – which unfortunately remains the default design principle governing assistive technology – barrier-free design was motivated by the aim of increasing the extent to which people with disabilities could participate in areas of human life, from personal maintenance and family life to education, employment and community activities. Yet, designing products and environments for specific populations create products with a stigmatising medical or technical appearance. These products are frequently more expensive, harder to find, unreliable and difficult to repair.

Early on, many advocates of barrier-free design and architectural accessibility recognized the power of the notion of addressing the common needs of all

people, with and without disabilities. After all, many of the environmental changes needed to accommodate people with disabilities could benefit everyone. Hence the goal of addressing the full scope of human accessibility and creating products and spaces accessible to and usable by all people to the greatest extent possible. Disability-accessible design tended to produce separate facilities for people with disabilities (a ramp set off to the side of a stairway at an entrance or a separate, wheelchair-accessible toilet stall); UD advised designers to provide one solution that can accommodate people with disabilities as well as the rest of the population.

UD is therefore adaptable not (merely) accessible design. An adaptable dwelling unit has all accessible features that a fixed accessible unit has but allows some items to be omitted or concealed until needed so that the dwelling units can look the same as others and be better matched to individual needs when occupied. Similarly, a UD product or tool is one that is easily adapted for use by people of different ages and abilities, not one that is purposively built to be useful for a specified ability level, or, at the other extreme, designed for a 'normal' population that excludes those who fall outside of that arbitrary range.

In Europe, Universal Design is more frequently referred to as 'Design for All' and, like the US, it has been mandated, either explicitly or implicitly, in an ever-increasing number of policy areas by legislation. The European Institute for Design and Disability (EIDD) was originally established in 1993 to promote UD principles, changed its name to EIDD-Design for All Europe which now has active membership from 22 European countries. UD principles are enunciated in national legislation of most European countries, such as Ireland (Disability Act, 2005), Italy (Law 1 March 2006, n. 67), and in France (Loi n° 2005-102).

In the US, Section 504 of the Rehabilitation Act, 1973 implicitly adopted the UD perspective, as did the original Education for Handicapped Children Act, 1975. The Fair Housing Amendments Act, 1988, and accessibility guidelines issued by the U.S. Department of Housing and Urban Development in 1991 furthered the spread of the UD principle in housing.

In the developing countries, the same trends that motivate UD also obtain; but in these countries the need for UD is arguably greater since specialized assistive technology is much more costly and harder to find, and the stigma of disability can be much greater. In these areas of the world UD is an obvious alternative to accessible design since it can be more generally available at lower costs than specialized products or environments (WHO, 2011).

In the hands of creative designers and planners, UD has proven itself in many contexts. Of course, the challenge of making products and environment that can 'forgive' physical differences or adapt to a wide range of capacities, while not having a medical or institutional appearance and be marketable is not an easy challenge to meet. UD demands a sensitivity to and understanding of the broad range of human abilities throughout the lifespan. This sensitivity is guided by the seven principles of UD.

Principles of Universal Design - analogies for law and policy

In order to evaluate existing designs and to provide a format for the design process, the founders of UD set out seven principles, each with guidelines (Story et al., 1998). Together these represent the first level of operationalization of UD. Although they were not intended to be used in this manner, the first five of these principles are, with modest alteration, directly applicable to the design of universal policy and law (table 1).

The first two principles contain the primary message of UD, namely that product and environment design should be equitable (Principle One) in the sense of being useful for people with diverse capacities (Principle Two) and flexible, in the sense of accommodating a wide range of individual preferences and capacities. Equitable use, the guidelines tell us, means that whenever possible the manner in which the product or environment is used should be identical or at least equivalent, and no user should be, by virtue of the design, segregated or stigmatized. Use is flexible when choice in method of use is provided, consistent with each user's abilities, pacing and preferences.

Table 1. The principles of Universal Design- Story, et al. 1998

Principle one: equitable use The design is useful and marketable to people with diverse abilities.
Principle two: Flexibility in Use The design accommodates a wide range of individual preferences and abilities.
Principle three: Simple and Intuitive Use Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
Principle four: Perceptible Information The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
Principle five: Tolerance for Error The design minimizes hazards and the adverse consequences of accidental or unintended actions.
Principle six: Low Physical Effort The design can be used efficiently and comfortably and with a minimum of fatigue.
Principle seven: Size and Space for Approach and Use Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

An equitable and flexible social policy would, by analogy, be designed to meet the needs of as many people as possible, congruent with the overall objectives of the policy or law, be it income support, education, employment, transportation or housing. The analogy between social programs and products and environments is in fact quite close with regard to these two principles. The idea is that social programs ought to be designed so that their objectives are met by as many people as possible, and so takes into account, in design and

implementation, the full range of human variability in capacity and need. What policy flexibility means in practice will depend on the program's objectives and how variations in human capacities are factored into implementation plans to achieve those objectives for different individuals. For example, transportation policy can meet its universal objective of moving as many people as possible by taking into account the needs of people who are blind, but perhaps does not need to take into account people with depression. For obvious reasons, equitable and flexible policy will not segregate or stigmatize individuals or groups.

The next two principles of UD deal with the level of complexity of, and preparation required for the use of a product or environment. Principle Three states that designed use should be simple and intuitive, consistent with user expectation, and accommodate a wide range of literacy and intellectual ability. Principle Four adds the requirement of informational accessibility, the requirement that instructions and other pre-requisites for use be informative and, depending on the user's sensory abilities, 'legible'.

The analogy here is also straightforward. Social policy must be designed so that its objectives and benefits are transparent to all. In part this means for social policy exactly what it means for products and environments, namely clear and accommodating information about the program so that each person can benefit from it in ways appropriate to his or her needs. As well, the injunction against complexity and obstacles to information flow entail, in the arena of social policy, the twin demands of transparency and democratic participation in social and political life. Social policy is, after all, a product of the political system – an output which like any product or environment is intended to meet needs. Therefore, universal social policy would demand the free flow of information between those who design and those who use and benefit from social policy.

Finally, the Principle Five highlights the importance, when designing products or environments, of tolerance for error. This means that when products and environments are designed for maximal flexibility, to accommodate a variety of users, the possibility of mistaken use, creating hazards, is also increased. To

deal with this side effect of flexibility, designers must first be aware of its possibility and design in ways that minimizes hazards. More generally, this principle can be understood as counselling vigilance for the misuse or inappropriate use of universally designed environments.

This is a potentially powerful principle for social policy development. For social policy and programs from legislation, the analogues of product misuse and dangerous environments are the unfortunately common anomalous outcomes that undermine, when they do not contradict, the desired objectives. Policies and laws that seek to employ people but which, because of bad design, discourage people from working have failed to heed this principle. Similarly, programs that seek to ensure economic self-sufficiency for people, but which can be manipulated by those not in financial need, also fail. How these policy defects can be designed out is, of course, an enormously difficult challenge. Still, UD advises sensitivity to the effects of programs and legislation on people's lives, and a vigilance to ensure that flexibility does not undermine effectiveness.

Universal social and legal policy -- tentative examples

Can we imagine what universal social and legal policy would be like? In some cases, no imagination is needed. As already mentioned above, there are several examples of UD-inspired legislation already in effect. To be sure, these are often restricted in scope, and qualified in ways that limit their universality. Nonetheless, they can be used as examples of the implementation of principles of equity and flexibility in law. For present purposes, instead of looking at the details of existing models in legislation and policy, it will be profitable to be more speculative and consider generally how universal design principles might play themselves out in key areas of law and policy. We consider two examples; health care policy and welfare or social support policy. Universal design in health care: universal health care

Universal design in health care: universal health care

It should not come as a surprise that the best example of a 'universally designed' health care policy is a single-payer, publically administrated and funded, universal health care system. Of the existing examples in high resource countries, Canada's remains the most comprehensive and politically secure. In Canada, coverage is universal in the sense that every citizen qualifies for the same, comprehensive, level of health care regardless of medical history, personal income or standard of living; coverage is not restricted to any one part of the country but is portable, and all insured persons have reasonable access to all health care facilities (and all health care providers have reasonable compensation for their services) (Canada, 2005). Although many health care systems in the world have universal coverage, as for example Spain, Canada is unique in not have a complementary private system operating simultaneously (Blendon et al., 1991).

It should be said it is not accurate to say that health care in Canada is totally accessible, in the sense that the buildings, offices and other facilities themselves meet the requirements of universal design; like all other countries, Canada has this challenge still to meet. But at the policy level, the Canadian health care system arguably satisfies the UD principles. Any move away from this sort of health care arrangement, and certainly any unregulated and privatized approach, will violate the UD principles of equity and flexibility: almost by definition, a non-universal health care system includes provisions that prejudicially distinguishes people with 'pre-existing health conditions' from those without.

At the same time, despite its virtues, there is no reason to believe that the Canadian health care system accommodates, or even acknowledges, the other three UD principles of simplicity, informational accessibility and tolerance for error. These criteria are primarily administrative and procedural: features of how services are delivered, rather than what services are delivered. Unfortunately, centralized and government-run systems, especially those of the expense and complexity of health care systems, are not always efficiently administrated and managed. To be sure, the administrative costs of the

Canadian system of health delivery is far lower than that in the US, especially considering that the Canadian system achieves nearly 100% coverage, whereas the private component of the US covers between 75-80% of the population (Guyatt et al., 2007). But the administration the Canadian system would need to be substantially altered in order to live up to the procedural UD principles.

Universalistic welfare programming

Universalism in social welfare or social protection design is not a new idea. Richard Titmuss, an English theorist responsible for much of our understanding of the philosophy of welfare in the English speaking world, argued that, from its inception in the late nineteenth century in Bismarck's Germany, it was thought to be essential to welfare policy that services be made available and accessible to the whole population in order to avoid loss of status, dignity or self-respect on the part of service users: "There should be no sense of inferiority, pauperism, shame or stigma in the use of a publicly provided service; no attribution that one was being or becoming a 'public burden'" (Abel-Smith, 1987: 146).

Universalism could only be achieved, Titmuss argued, if welfare was made available, not as a special service grounded in charity or compassion – or as we might also say, in response to 'special needs' – but a universal public service grounded in "the social rights of all citizens to use or not to use as responsible people the services made available by the community in respect of certain needs which the private market and the family were unable or unwilling to provide universally" (Abel-Smith, 1987: 146). Universal provision was essential not merely to avoid stigmatization, however. If these services were not provided "for everybody by everybody" the chances were that they would not be provided at all. Moreover, the realization that prevention of the 'social ills' associated with poverty, disease, neglect, illiteracy and destitution was far more efficient than responding after these ills had manifested themselves, the early architects of welfare soon learned the lesson that to be effective in action in a highly differentiated and economically unequal society, these services had to be delivered universally.

In the last two decades, universalism has had to face the claim that it is economically inefficient and that selective or targeted policies, based on needs assessment or means-testing are better at targeting assistance to the economically weakest part of the population, namely those unable to purchase insurance and services on the market for themselves (Berkowitz, 1989). Economists also argue that the stigma associated with targeted assistance helps to keep costs down by reducing the demand for the services. Such a system, it is hoped, supports only those who are 'truly needy'. Universalism is thus opposed to the political principles that support only the truly needy and promote the privatization of social services for others.

This purely economic consideration has been very popular. The opposing position, which sees welfare as a right of citizenship, is a manifestation of a universal sense of equality, which underwrites UD principles. Here the argument is that a social commitment to meaningful equality demands equal sharing of the benefits and burdens of citizenship (Marshall, 1965; Culpitt, 1992). Moreover, the current preference for targeted welfare programming is often supported by the claim that universalistic welfare policy is more expensive, although there are in fact no studies that actually show that to be the case.

There are no existing examples of purely universalistic welfare systems – although Sweden's social support system probably comes the closest. Nonetheless attempts have been made to sketch out what such a system would look like. Welfare economist Bo Rothstein, for example, has argued that a universal system would consist of three interlocking components: 1) publicly produced and universally available services such as health care, basic education, care of children and of the elderly, as well as publicly regulated and subsidized housing; 2) a system of universal flat-rate benefits tied either to citizenship or residency, such as basic pensions and child allowances; and 3) a mandatory social insurance system, in which benefits reflect earnings on the labor market and are designed to provide income security, by means of supplementary (earning related) pensions scheme, sickness pay, and parental insurance (Rothstein, 1998). Together, such a system would, he claims, lower

the costs associated with providing 'special' services to populations defined by complex eligibility requirements.

Ironically, a universal system of this sort might not have an identifiable 'disability policy' at all. But that is as should be expected since 'disability policy' is implicitly targeted or selective by its very nature. A universal social support system would likely set standards of participation in major life areas – education, employment, housing, transportation, family and personal care, medical care and so on – and then seek to secure equalization of opportunities and human rights for each area of participation in resource terms and in accordance with these standards. Individuals with different levels of need would access different resources that are appropriate to the standard level of participation for that area suitable for the individual. Public provision would be universalized by satisfying the principles of equity and flexibility in the provision of basic needs, across the full spectrum of normal human variability. Such a system, subject to similar procedural and administrative concerns already mentioned in the case of health care, would very likely satisfy the UD principles.

Universal policy and law: the need for basic research

This paper is an attempt, first to create analogues of principles of UD that are applicable to law and social policy, and secondly to look at potential examples of the application of these principles to law and policy in order to clarify, and recommend the use of, the underlying principle in Irving Zola's seminal paper on universalized disability policy. UD principles, we have argued, are directly applicable to social policy and law, and we have suggested that in two major social policy areas, health and welfare, that applications of these principles is feasible and, in some restricted examples has actually been implemented in these policy areas. Our primary objective of showing the feasibility of universal policy and law has been satisfied.

Research is needed, however, to be more precise about how these policies live up to the promise of universal design and accord with UD principles. The value

of this research, moreover, would be two-fold: not only could we assess existing programs against the principles of UD, we could also use these programs as further guides to devise more specific and operational guidelines to test existing or proposed social programs. This methodology is appropriate where, in the absence of a 'gold standard', our goal is to further refine our understanding of the objectives of social policy.

Basic research is also needed to construct the operational principles and guidelines that will move universal disability and law from theory to practice. To be workable, guidelines presume outcome measures and other techniques for assessing success and failure. These measures will necessarily involve both health and non-health determinants of basic human functioning and capacity. The Convention on the Rights of Persons with Disabilities delineates these basic areas of human life, areas in which everyone, around the world, has a moral claim to participate, and can therefore serve as a template for this research.

The aim of a universal policy is to enhance the capacities and opportunities of all citizens, which in turn makes possible the achievement of participation in those areas of life that can plausibly be argued to be basic for human life. What areas of life these are, how they interact and their ranked importance, are matters that stand in need of basic research, empirical and theoretical. Universal disability policy and law can only move from speculative ideal to concrete reality when this research is accomplished.

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