

Equalization and Participation for All: Swedish Disability Policy at a Crossroads

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Abstract. The political line in Swedish disability policy advocates the use of generalized solutions in order to fit potential needs of the largest possible group of people and, where needed, special solutions to bridge the remaining gap between the generalized level of accessibility and additional individual needs. This is referred to as the disability perspective (DP). The DP has embraced two tracks: one that pertains to generalized solutions that promote an overall high level of accessibility and usability, and another one that pertains to different types of individual support for people with disabilities. The present study is a self-reflective inquiry on key issues for the development of future disability policies. Five experts entered a discussion about the pros and cons concerning the DP. This confirmed or refuted assumptions, dilemmas, themes as well as reoccurring patterns in the political viva voce procedure that has formed the contemporary disability policy. Over the course of time, the experts believed that the DP had nurtured a belief that there is a dichotomy. This may have created an imbalance in the relation between the DP and policies such as those concerning healthcare and social care. With a clearer focus on interdependence, the experts saw synergies between needs for assistive technology, assistive products and the requirements for the built environment.

Keywords. Policy-making, accessibility, Universal Design, interoperability

1. Introduction

In retrospect, people with disabilities have often been secluded from the rest of the Swedish society through discriminatory beliefs and a mixed ambition of either protecting this group from the rest of the society, or isolating the society from people with disabilities. Through conscientious policy-making, the Swedish welfare society has maneuvered from this impasse of stale thinking into an open society for all, regardless of individual abilities and characteristics. National initiatives during 1950s and the 1960s laid the ground for inclusion of people with disabilities in society based on principles of inclusion and normalization [1]. The difficult housing situation of the 1950s and 1960s for this group was deliberated by the media, which resulted in a new housing built to accommodate the needs of people with functional or visual impairments [2]. In addition, minimum requirements based on necessary space for wheelchairs users was introduced in the national building act to improve conditions for

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accessing or egressing a building, stairwell and passages as well as for using hygiene facilities [3]. In 1975, the original concept of access was converted into the modern concept of accessibility. Accessibility in the built environment focused on the removal of obstacles for people with locomotory limitations and those who experienced difficulties when navigating in or around the built environment, both exterior or interior. The 1960s and 1970s also brought reforms in education, social benefits and work opportunities which steered in a more inclusive and non-discriminatory direction.

Conveniently positioned on this cornerstone, Swedish policy for people with disabilities started to evolve in a right-based manner where social support and services were granted in legal acts. In 1994, the disability policy was reformed in that direction. At the same time, a new authority was founded, the Swedish Disability Ombudsman (SDO, Handikappombudsmannen). This new authority started to define the rights of people with disabilities and prioritized both grants and subsidies oriented to individuals and in need of individual support and assistive technology, as well as mainstreaming accessibility actions to increase the level of accessibility generally in the whole society. The credo by the end of the 1990s was that “generalized accessibility is always first choice,” which echoed the reorientation that had occurred in the Swedish disability policy [1].

In 1999, a national action plan for policies for people with disabilities *From Patient to Citizen*, a national action plan for disability policy (*Från patient till medborgare, en nationell handlingsplan för handikappolitiken* [1]), was formulated and in line with the explosive title, the report became very influential for the second millennium. Particularly, it supplied a strategic instrument for Swedish disability policy, the disability perspective (DP). This perspective was introduced in order to reform the existing view on disability which was restricted to needs of a small group of people that were addressed with policies for health, rehabilitation, support services and assistive equipment. The term DP covered (and still covers) design-related and environmental problems in the built environment, infrastructure and the whole society that created obvious and unintentional obstacles in everyday situations for all users, not only users with disability.

In consequence, changes of a general nature that targeted accessibility issues in the public built environment were prioritized, whereas compensatory actions, mainly various assistive technologies, for individuals with disabilities assumed a secondary role. The DP acknowledged the so-called social model of disability, in which environmental factors, including attitudes and physical obstacles, constitute the main barriers for including people with disabilities on equal terms in the welfare society rather than the impairment or limitation itself [4]. It also provided a direct action-related response to the UN definition of disability, handicap and impairment [4].

In this paper, the implication of the DP is somewhat simplified, partly due to the particular scope of this paper, partly in order to forward the intrinsic dialectic that it holds:

- the comprehensive and generalized understanding of accessibility with its effects on the whole society (GA), and;
- the personalized understanding of accessibility with its direct effects on an individual with a particular requirement (PA).

To some extent, it is fair to say that the driving forces behind the two understandings of accessibility can be construed as being contradictory; i.e.

- in the built environment generalized accessibility, GA, relies on a multi-disciplinary approach that tends to summarize human variations in abilities into approximate and rough entities,
- while individual accessibility, PA, revolves around a personalized approach to cope on a daily basis with barriers, intentional or unintentional, that constitute direct conflicts between the individual's set of abilities and the design solutions that are in vogue at the particular moment.

Furthermore, the DP prioritizes GA over PA - general solutions are always first choice, and special solutions secondary - and the GA gains general validity through the societal perspective. However, for PA, the fit between person and the type of assistive technology that is intended to be used has full supremacy since this fit promotes their independence and participation in society. The continuous move from the GA to the PA, could explain why the Swedish implementation of accessibility sometimes appears as two distinctively separate lines of development, a general one that is found in the built environment, and a personalized one that is found in the development of various assistive equipment and technologies.

The DP was and still is an essential mechanism for Swedish disability policies that were formulated for the period of 1999-2016 [1,5] but also for a decree that assigns responsibility to representatives of the state to function as exemplary models, and, thereby, demonstrate an improved level of accessibility [6]. The DP promoted the acknowledgment that people with disability had the same rights as any other Swedish citizen, thus, putting a definite end to a long-lived and lingering seclusion of people with disabilities. The DP also led to a need for reforming the SDO, since its *raison-d'être* became closely associated with discrimination and equal rights for people with disabilities. In 2006, a special coordinating authority was established, The Swedish Agency for Disability Policy Coordination (HANDISAM). In 2014, this authority was reorganized and merged with the former Swedish Institute for Assistive Technologies, SIAT [7] and re-named the Swedish Agency for Participation (MFD). The Swedish Agency for Participation (Myndigheten för delaktighet – MFD) is a key player in the field of equalization of opportunities and participation. Concretely, the DP approach resulted in the definition of the concept of 'easily removable obstacles' (ERO) in existing buildings and open public spaces (in Swedish, 'enkelt avhjälpna hinder') by the national Board for Housing, Building and Planning (BHP, in Swedish Boverket) [8]. The ERO clearly defined accessibility issues such as access and egress conditions, difference in floor levels and hygiene conditions as particularly important to address in the existing built environment.

1.1. Aims and Purposes

The year 2016 is an important year, not only the first year that lack of accessibility to public environments is a ground for discrimination [9], but also the end of a 15-year period with two disability policy strategies, the first one 2000-2010 and the second one 2011-2016. In addition, 2016 is important since the MFD is developing a 5-year strategic plan for 2017 to 2022. This strategy will contain both goals from the previous strategies, since the main conclusion from the past 15 years is that the pace of improving accessibility in the Swedish welfare society is taking a considerable amount of time.

It goes without saying that the ambition for the new policy is to make it both more targeted and goal-oriented, so that the long-term policy will be even more efficient and systematic than before. However, one fundamental problem remains to evaluate: the efficiency of the DP approach. Given the integrated position of GA and PA in the DP, this duality is of special interest. Two essential questions materialize when discussing the relation of the GA and PA:

- Is the relation mostly harmonious, or dominantly discordant?
- Does the relationship display signs of wear and tear?

In analogy with yin and yang in Chinese philosophy, the fundamental question is whether the DP approach can serve as a key mechanism in the strategic thinking for the next policy period.

2. Methodology

This study is a case study that used a self-reflective inquiry approach in order to activate the inner and outer arcs of attention of officials, employed at the Swedish Agency for Participation, MFD [10, 11]. The inquiry involved open-ended questions that were posed during an interview situation or in a questionnaire.

2.1. Interviewees

The group of officials consisted of five experts. Two interviewees were experts in Swedish disability policies concerning accessibility and participation in general, but also for people with disabilities in particular. These officials were males with a previous activity at the agency or predecessors for about 22 years. Two female experts also took part in the group. One was a physiotherapist, with a focus on assistive equipment and technology. This expert had an accumulated experience from this field of expertise of 30 years, 8 years as practicing therapist and 22 years as official at the agency or predecessors. The other was expert in architecture and built accessibility with an experience of 16 years at the agency or predecessors, and also as practicing architect.

The fifth expert was male, a trained architect, with a short period with the authority, only one year, and experience from practicing architecture. This person acted as discussion leader and distributor of the questionnaire.

Table 1. Overview of themes for interview and questionnaire.

Item	Question themes
1	What does the disability perspective, DP, mean for you?
2	According to you, which are the most essential key components of the DP?
3	Do you believe that the DP has influenced the evolution of Universal Design and the one of assistive equipment? And, what about accessibility?
4	How do you define Universal Design in your own words?
5	Do you think that Universal Design thinking and the development of assistive equipment benefit from a mutual influence?
6	Do you believe that a similar mutual influence would promote innovative thinking in buildings and the built environment?

2.2. *Interview and Questionnaire*

The group of experts was invited to a 1.5-hour interview to discuss the current state of Swedish disability policies, its background and foreseeable future tendencies. The email-based invitation contained six questions, which in a personal tone asked the expert to reflect upon the themes. Three experts managed to arrange their agenda, so that a meeting could take place. The architect-expert did not manage to free her calendar. She submitted her answers in a mail after the meeting. The questions are listed in table 1.

The interview had an unstructured format; the questions were posed with approximate phrasing that suited the on-going discussion. The interview was recorded, so that striking clarifications or poignant statements could be retained. The questions provided a thematic approach for structuring the paper and arriving at a working hypothesis concerning the desired continuation for future Swedish disability policies.

3. Results

This section is divided into four sections. The first, second and third parts are summaries of the discussion with the three MFD experts that were combined with the written comments from the fourth expert. These parts focus on decisive moments in the experts' discussion. The fourth part summarizes the exchange of ideas so that conclusions on key issues for the development of the future Swedish disability policy can be formulated.

3.1. *The Disability Perspective and Its Key Mechanisms*

The guidelines, which the MFD formulates approximately every five years concerning an improved level of accessibility for state organization [6] depend upon the DP fundament. One of the policy experts stated that the DP was a conscientious move from the personalized compensatory approach concerning disability in order to affirm the societal responsibility. Globally, the four experts' different understanding of the DP described a continuum that stretched from the GA to the PA. This continuum was part of a fundamental human right: to have access to and be in reach of the fundamental things in life [12] The experts' view on the GP revealed some similarities with Plato's theory of forms [13]: an inclusive world is a reflection of an ideal world. It describes a perfect harmony between intra-human abilities, inter-human and human-environmental relationships. In comparison, the lived world is an imperfection, hence, the GA adjusts discrepancies in inter-human and human-environmental relationships, while the PA compensates intra-human disabilities in relation to the surrounding world. The effects of the GA and the PA manifest themselves in the universal human right of equal access to the ideal world for everyone, regardless of personal abilities. The notions of accessibility, equality, inclusion, participation and usability are tools for realizing an accessible world, with the distinction that generalized measures require individualized detailing.

3.2. *The Relationship between the DP and Universal Design*

The new disability policy for the period 2000–2010 was conceived as a measure to reboot the Swedish understanding of the inclusive welfare society. This called for a small group of policy makers within the SDO who, with limited contacts with representatives from other authorities or interest organization in defense of disabled people's right, construed the notion of DP. To some extent, it integrated some parts from the Universal Design movement, UD, but largely, the DP gained inspiration from the European Design for All movement.

The DP was a necessary strategic policy move in order to unite two tendencies that were apparent in the beginning of the new millennium: on one side, individual forms of societal support greatly expanded during the 1990s, and, on the other side, the quest for generalized accessibility that has started to interpret the defined minimum recommendations and requirements as being maximum recommendations and requirements without a logical analysis of the effects of implementing this in the built environment. The DP raised an awareness of the need to unify the individual and generalized approaches with the ultimate goal of achieving a flexible and inclusive society in which all citizens can participate.

The DP was and still is a starting point when entering into a discussion on appropriate measures to conceive accessible environment for all. In that sense, the UD becomes a tool for conceiving accessible solutions. The experts noted that assistive technology that compensates for a disability can be used as a starting point for identifying areas where generalized accessibility improvements are needed, for example universally accessible media, organizations or built environment.

3.3. *UD versus Generalized and/ or Personalized Accessibility*

The final interview questions open with a discussion on necessary changes that the existing framework for understanding of the DP has to undergo in view of a new disability policy. Parallel to the changing boundaries between assistive technology and user-centered product design, the experts detected the need for a stronger focus on user values even in the design of buildings, infrastructure and various services.

If the approach of 1967 could be characterized as “we do it for them, i.e. the group of people with disabilities,” [14] the credo for 2016 should be “by focusing on differences in human abilities, we create a welfare society for us all.” In that sense, the underlying implication of accessibility requirements that are merely minimum requirements must be paired with an innovative insight about aspects that increase the level of usability, and, thereby, the perceived usefulness by a large and diversified group of users. In the new policy, usability becomes an essential concept for adding power to a merging of the GA and the PA and sanctions the PA approach for continued use in the policy for 2017 to 2022.

This promotion of usability for a large and diversified group of users would also emphasize the need for expanding the policy from the dual focus of monitoring-evaluation to a triple focus of monitoring-evaluation-innovation. Innovation implies a stronger focus on exemplary models of accessible solutions that stretch from an artifact, product level to a building and physical planning level. A combination of UD and design theory would give a necessary edge to design professions to cut through stale assumptions and beliefs and expose the raw mechanics in the dichotomy GA-PA of the Swedish DP approach.

3.4. Conclusions on DP, GA, PA and UD

Globally, the experts' discussion on the origins and the future development of Swedish disability policy revolved around the concept and its evolution. The DP was discussed in different contexts resulting in various aspects. Hence, the discussion supported the two following conclusions:

1. DP is cross-disciplinary by nature and nurtures two approaches for the removal of inhibiting factors and obstacles: (a) the societal understanding that improves a general level of accessibility to give more equal opportunity to education, housing, transport and work, GA, (b) a personalized understanding that compensates for a disability, which an individual might experience due to the design of education, housing, transport and work (PA).
2. Attention should be focused on the two approaches which comprise the DP, in order to identify and understand the interdependencies and synergies between them. This understanding can result in a cross-pollination which can enrich both approaches. For example, improvements in general accessibility in the built environment can be achieved by taking on board developments in the field assistive technology so that features/products that are of benefit for persons with disability become available for the whole society. In turn this can free resources in the field of assistive technology that can be used to tackle areas where accessibility for persons with disability is not yet met with general measures. This can lead to a modern welfare society accessible to all regardless of abilities/disability.

In contrast to the yin and yang symbol, the four experts saw a potential risk for rupture in the DP perspective, so that the GA would enter into a state of inertia due to the lack of input from the PA. On the other hand, the experts saw a considerable potential for the PA's impact on development of new information and communication technologies in combination with innovation and robotics. Previously regarded PA features are becoming general accessibility features and are moving the boundaries between assistive technology to compensate a disability, mainstream commercial products that offer personalized features and the architectural design of new buildings and city planning.

4. Discussion

In the Swedish policy landscape around the turn of the millennium, the focus was on generalized accessibility. The DP formed the basis for activities to mainstream accessibility in the whole society. In 2008 HANDISAM concluded that there was little research, which could be used by policy implementing authorities, on how disabling processes could be understood [15]. The question was how inaccessibility arises and why it has not been rectified? This was confirmed in part by the MFD in a report to the government in 2015, which noted that the area is multifaceted and introduced the concept of research on participation [16]. The report did not capture the conclusions described in this paper i.e. the two parallel processes of the DP - one for general accessibility, GA, and one for the development of individual support and assistive technology, PA. In the description of knowledge necessary in the field of digitalization,

however, these two parallel processes, on which this paper focuses, are described as a whole, rather than as separate processes. The need for generalized accessibility, similar to the universal design concept, and assistive technology that can support the individual and facilitate personal participation and independence, i.e. security alarms is forwarded as a converging interest.

The development is rapid in the area of assistive technology, mainly in connection with digitalization. Features and products developed specifically to compensate for persons with disabilities are extensively integrated in mainstream products. It is not uncommon that specific solutions that compensate are software or mobile applications. In a parallel track, the modern welfare society is becoming more and more automatized and connected to the Internet. It is no longer science fiction that robots, which are managed over the Internet, can give support to humans and the use of robotics is expanding; i.e. robots for cleaning, for cutting grass and for cleaning the swimming pool.

In comparison, accessibility of the built environment, transport, information, communication, products and services has a somewhat stricter division that depends upon the particular category. However, even these areas are converging, mainly due to users interconnecting in the in daily life. It is probable that glitches will occur in the process of connecting the different areas, and, thereby, create new disabling situations. This potential fragmentation, which is inherent in the built environment, transport information, communication, products and service, calls for a more user-centered approach that is similar to the one used in assistive technology.

In consequences, architects, who want to conceptualize generalized accessible modern buildings have to take this in account, since digitalization in combination with a transdisciplinary approach may compensate for functional limitations. In a similar way, AT developers have to be well-oriented in the field of digital technology in order to grasp how synergies with, for instance the built environment, can be created.

In conclusion, the discussion among the MFD experts suggested a potential danger for a widening gap in the DP, since the two parallel processes GA and PA are following a different pace in their development. For a successful future, the two parallel processes have to be recognized as being highly co- and interdependent, so that they interact, intertwine and generate synergies which can result in positive outcomes for a diversified user group. Deep knowledge of human needs will form the basis for developing design solutions for the DP that concern both the GA and PA approaches.

Today, policy makers are part of a more complex world with a large potential to both prevent and remove perceived and physical obstacles in the welfare society. The role of policy makers is to contribute to an expanded and improved accessibility for all regardless of abilities and characteristics, by implementing a universal design approach that takes on board developments in the field of assistive technology, other technologies and the built environment. Confidently, Swedish policy makers can look forward to a new policy period where reflections on DP, GA and PA can be tested, and, potentially, promote a sustainable development of the whole Swedish society.

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