Policy

Bridging policies and practice: challenges and opportunities for the governance of disability and ageing

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Abstract

Introduction: In the context of an increasingly ageing society with a growing number of persons diagnosed with chronic disabling conditions including dementia and persons with disabilities, ageing and disability represent two policy fields which need to be jointly re-thought. So far, policymakers and other political actors have not adequately reacted to these changing demographics.

Description of policy and practice: The two policy fields are based upon different presuppositions. Also, disability and ageing interest groups set different agendas. As several political actor groups with diverse interests and goals operate in the political space, efforts to bridge policies and practices in ageing and disability are confronted with several challenges.

Conclusion and discussion: In order to create a policy framework for disability and ageing, shared political priorities need to be developed. It is necessary to re-think current disability and ageing policies and the objectives formulated by diverse interest groups in both fields, and future policies should not only focus on ‘active/healthy/normal ageing’ vs. ‘non-healthy/non-normal ageing’. Overlap of contents between disability and ageing policies exists with both fields informing one another. This mutual influence will shape policymaking and policy practices with regard to an ageing population with a growing number of persons with disabilities.

Keywords
governance of disability and ageing, policy and practice, bridging agendas and objectives

Background: changing demographics and political action

In the context of an increasingly ageing society with a growing number of persons diagnosed with chronic disabling conditions, including dementia and persons with disabilities, ageing and disability represent two policy fields which need to be jointly re-thought. So far, as was highlighted by the National Institute on Aging (NIA) [1], policymakers and other political actors have not planned for the long term with regard to the changing demographics and the fast pace of population ageing. However, as Vladimír Špidla, EU Commissioner for Employment, Social Affairs and Equal Opportunities, argued in a recent speech the window of opportunity is still open for a timely response to Europe’s new demographic order [2]. He also referred to the importance of focusing on active ageing and the economic possibilities arising from Europe’s ageing society.
In his speech—reflecting the prevalent attitude of political actors towards the issue—Vladimír Špidla addressed several key challenges evolving from changing demographics and from employing old-established policies and practices: first, demographic changes did not occur suddenly during the past few years as some may suggest but have been the result of a gradual process. The problem is, that the formulation of new policies and implementation of new practices that are responsive to the new demographic context lag behind. Second, the discourse on ageing is predicated upon a dichotomy between ‘active/healthy/normal ageing’ vs. ‘non-healthy/non-normal ageing’.

At present, the emphasis is on active/healthy/normal ageing, something that will not be politically sustainable in an increasingly ageing society with a growing number of persons with long-term conditions, dementia and/or disabilities [3]. Third, economic sustainability can also be used as an argument to question policies and practices for elderly and disabled persons as the costs for these groups are perceived as intensive and unaffordable [4].

The second and the third arguments are both important for the policy fields of disability and ageing and they shape the formulation of a new policy framework for an ageing society. Both show that it is necessary to jointly re-think the two policy fields ageing and disability to facilitate more adequate policies and practices in the context of a society, which is increasingly understood as being made up of non-healthy, disabled and costly citizens. Old age as a category and concept is socially constructed [5, 6] as is disability. Both, age and ageing are increasingly medicalised [7]. While the interaction of social and biological factors ‘create’ disability, it is not possible to sharply distinguish between the biological reality of a disability (the person affected) and the social construction of a disability [8]. In this sense, social construction refers to a ‘process’ [9]. Similarly, the category ‘age’ has transformed within a short period during which the medical successes in the treatment and management of lifespan limiting diseases was celebrated, to something that identifies age as a risk factor (for example in the context of different forms of dementia). The social construction of the process of ageing as a lifelong phenomenon needs to be distinguished from ‘old age’ or ‘the demented person’ as a distinctive category or endpoint [9]. We grow older and we may be demented and/or impaired (as a biological ‘reality’), but what is at stake here is what happens to the ‘group’ of elderly, demented or disabled persons in the course of social interaction and negotiation about what old age is, dementia or disability (as a social construction, such as old age, dementia and disability as dependence, loss of autonomy and control [10]).

For example, the sole focus on promoting healthy ageing and the costs associated with ‘transforming’ non-healthy persons into healthy persons represents a ‘normalisation process’ which will neither be politically nor economically viable considering the global change in population demographics. Moreover, the unipolar focus on ‘health’ and ‘normal function’ ignores the spectrum of human functionality, human resources and the diverse enhancing or inhibiting social environments in which human beings operate. Hence, taking on board and adopting achievements of the disability movement and developments in disability policy may shape ageing policies and practices in two ways. It may be a way of empowering persons who are understood as ‘not normal’. But equally critical it is also an opportunity to bring about a shift in public attitudes towards disability and impairment, which will be ‘helpful’ in a world where the majority will not fit into the category of ‘healthy’ and ‘non-disabled’ persons.

**From government to governance as practice**

Policy learning from and knowledge transfer and exchange between disability policies and ageing policies seem to provide an opportunity to adapt to changing situations [11]. Increasingly, knowledge transfer is not simply understood as a linear transmission from one set of experts to another but as an iterative, ongoing mutual learning and exchange process that involves a complex set of stakeholders or actors [12]. Adjusting the policy goals or strategies in response to past experiences and new information [11], is an effort to be made by all political actors groups in the respective policy fields. In the case of ageing and disability—both policy fields have an effect on the whole society—this means that not only governmental political actors groups and policymakers are involved, but also diverse political actor groups, such as senior citizen organisations, patient organisations and other NGOs.

The involvement of new and not only ‘traditional’ political actor groups in policymaking in new political spaces (besides parliaments and ministries) and focus on new topics, goals and strategies, can be understood as a shift away from well-established notions of politics [13]. This shift can be subsumed under the title ‘from government to governance’ indicating that the state is no longer the only responsible authority in the policymaking process [14]. Governance as a new field of political analysis and also as a new form of political practice which we term ‘governance in action’ is about characterising the pattern that emerges from the interactions of a range of political actors of which the state is only one. Governance refers to the outcome of all these
interactions and interdependencies among the diverse stakeholders [15].

In the context of the concept of governance, ‘participatory governance’ is most important with regard to the question of involving persons directly affected by certain policies. Participatory governance can be understood as the regular presence of these persons and groups when making policy decisions in the respective policy fields [16]. In practical terms, this participatory approach to addressing and solving practical social and economic challenges has been tackled in so-called Knowledge Networks or Communities of Practice (CoPs) [17]. In a variety of settings, policy learning will work in a more comprehensive way if the concept of participatory governance is used as a political practice, because the experience of a larger number of political actors can be incorporated into the policymaking and policy formulation process. Participatory approaches to governance—as representative citizen participation and the implementation of inclusiveness in policy action—are understood as a way to achieve socially accepted, sustainable and innovative policies and outcomes [16, 18]. Examples include various consumer-directed approaches to health care organisation, management and financing in the US that have received some positive endorsements from people with disabilities in terms of decision-making satisfaction and personal control. Most studies have been reported for long-term care arrangements where consumer direction has replaced agency-directed community care [19]. However, there is considerable demographic and geographic variability and caution is warranted in transferring these results to other health and social care contexts.

**Two policy fields: disability and ageing**

Policies related to ageing and disability will have to adequately address the needs of an ageing society and the experiences with earlier formulated policies will have to be incorporated into the policymaking process. The challenge is to overcome differences in the development of the two policy fields disability and ageing. Whereas the understanding of disability as a concept changed in political practice from medical categories, such as illness to human diversity and difference, the near opposite trend can be observed for the concept of ageing. In the past, ageing was understood as an integral process in the course of life, with increasing segmentation of the life course it was seen as a stage (namely the last stage of life) and as a result of medicalisation is now increasingly associated with and even perceived as a form of disease. Why did it happen that the concepts of disability and ageing developed in such different directions?

The increased medicalisation of ageing [7] is the cause but at the same time it is the effect of this shift in understanding ageing and formulating respective policies. In disability policy on the other hand, a long tradition and history of the disability rights movement and of disability related policies and laws have led to an increased acceptance of difference. Persons with disabilities have been mobilising to challenge social exclusion since the 1970s and the resulting politics of identity has challenged ways of naming and knowing disability, alongside demands for civil rights and social recognition, as Tom Shakespeare argues [20].

Persons with disabilities have been involved in policymaking since several decades and have learned that identifying individuals as disabled are social practices that involve the unequal exercise of power and may have major economic, social, and psychological consequences in some people’s lives [8]. Hence, the most important lesson learned from the field of disability policies refers to the question of what is normal and the impact of the concept of normality and the norm on certain groups within society. Norms are the basis and justification for exercising power over persons and groups, which do not fit into certain understandings of what is ‘normal’ [21, 22, p. 47–75 Lecture from 15 January 1975].

**Disability and ageing policies: different presuppositions**

The above-mentioned socio-political importance of the concept of the norm is one of the most effective obstacles in the context of bridging knowledge between disability and ageing. Elderly persons have already one form of stigma, namely age, and they do not want to be labelled with another stigma, namely impairment and disability, which is often understood as a lifelong condition. This could be the reason that some interest groups in the field of ageing may be reluctant to emphasise disability policies too much and may argue against an overlap of policies [23]. Equally, there are hints of resistance amongst disability groups to engage with older people [10], which may result from a perceived lack of awareness among representatives for older people’s organisations to appreciate the social model of disability [10].

When trying to integrate ageing and disability policies, it is important to differentiate between persons ageing with a disability and persons ageing into a disability which implies different life experiences and shapes different forms of social identity [23]. Hence, this fact builds the basis for another obstacle for bridging knowledge between disability and ageing as several interest
groups with diverse claims, aims, goals, different forms of lobbying and different political priorities operate in the political space. Nevertheless, interest groups in the field of ageing could learn a lot from disability rights groups and disability policies. Whereas disability rights groups are actively involved in policy formulation and focuses on participation in the policymaking process, the organisations representing older adults in many European countries are arguably more inclined to support traditional forms of policymaking and government action. The distance and lack of participation is particularly obvious in governing dementia [24].

A ‘common basis’ between disability and ageing policies is that both are built upon the negative perception of the groups of disabled and elderly persons held by large parts of society. Discrimination, prejudice, stigmatisation, medicalisation, a focus on incapacitation and institutionalisation underpin views of disability and old age and thus form or socially construct a uniform and homogeneous group. The exceptional position in the sense of being understood as deviant or not ‘normal’ and as not healthy is the glue within the respective ‘groups’ which can be reversed into a starting point for developing a new policy framework for an increasingly ageing society with a growing proportion of older people living with long-term conditions including dementia and persons with disabilities.

Creating a new policy framework: towards a ‘social model of ageing’

The ‘social model of disability’ shifts attention from individuals and their impairments to the ways in which society includes or excludes these individuals [25]. In analogy to the ‘social model of disability’ which points out that disability is a product of social organisation and can therefore be reduced or even eliminated when social barriers and social oppression are removed [25], a ‘social model of ageing’ could fulfil the same function for ageing and elderly persons. The formulation of a social model of ageing would incorporate some of the criticism that has been directed at the social model of disability and would facilitate what has been called earlier in this article ‘governance in action’. In turn, the formulation of a social model of ageing could have a positive impact on the social model of disability in that it re-conceptualises both ageing and disability as biopsychosocial processes that require flexible responses in ever changing societal and political contexts. Shakespeare [25] argues that some difficulties arise from the implications of the social model of disability, mainly regarding the distinction between impairment and disability and ignoring the presence of impairments: then, impairment-specific organisations are problematic, and eligibility for provisions and for curing disability-related medical problems also becomes a problem. A sole focus on environmental and social barriers implies a shift from the individual’s needs to removing those barriers which is of course important but should not obscure the fact that not only barriers have to be removed. As mentioned above, social construction-as-process and construction-as-product [9] are intertwined, and so are disability and impairment effects. The distinction between impairment (understood as ‘biological’) and disability (as ‘social/cultural’) is problematic [8], and the focus on ageing shows that it is impossible to ignore the effects of impairments on persons with disabilities when discussing disability policies. Public policies increasingly focus on impairment-related aspects of ageing and disability (such as ageing as the last phase of life, dementia or genetic testing for diverse forms of impairments) and it is necessary to adapt to these changing contexts. This does not mean to accept an understanding of ageing or disability as loss, dependency or deficit, but to highlight the relational aspect of both ageing and disability, which quite the contrary shows that it is imperative to remove social, attitudinal and environmental barriers—but at the same time to focus on the individual. Person-centred care—for example—would not be possible in an understanding of ageing or dementia that ignores individual experiences.

A re-conceptualisation of elderly persons in analogy to disability (as the interaction of individual, bodily experience with a socially made context) would bring about more opportunities for participating in policymaking and policy formulation for these persons. In this context, interest groups have to convince other political actors that new policies which do not only focus on the dichotomy between ‘active/healthy/normal ageing’ and ‘non-healthy/non-normal ageing’ are necessary for managing changing demographics at a sociopolitical level. Also, it is crucial that interest groups formulate shared political priorities—while demonstrating awareness of the diversity that may exist within the ‘group’ of elderly persons. Achievements in the field of disability policies show that a paradigm shift in focus on certain societal groups is possible—towards de-medicalisation, de-institutionalisation, user involvement and independence—facilitating active participation in policymaking.

Challenges and opportunities for the governance of disability and ageing

The above-mentioned paradigm shift is based upon the political will to re-think ageing that is embedded in
a societal will to reconsider old-established perceptions of elderly persons and to overcome an increasingly medicalised gaze on older adults, including persons with dementia. Employing a ‘social model of ageing’ would mean to understand ageing as a relational matter between society and individuals. Consequently, empowered older adults may challenge the existing social order, also means to view them as active agents engaged in societal and individual change processes, ultimately leading to a new, more inclusive social order.

First steps towards bridging knowledge between disability and ageing and hence, towards a shift in understanding of ageing and elderly persons—not as an additional stigma, but as a way of actively promoting their participation in policymaking—have already been taken. The ‘Graz Declaration on Disability and Ageing’ [26], for example, points out that it is broadly recognised that many of the disabling conditions for elderly persons are caused by society. The difference between action and inaction of people with disabilities vs. older people could be illustrated by many examples. While, for example, persons with intellectual disabilities consequently work on changing the societal gaze on their impairments [27], dementia—a condition primarily associated with advanced age—is still and increasingly understood as an individual problem.

Nevertheless, the Graz Declaration highlights two groups that can be identified that need special attention in terms of policy planning—one is the group of persons with intellectual disabilities [28–32], the other one is the group of older persons with functional dependency [26]. Policy reforms are vital to develop effective mechanisms to enhance participation and independence of these two groups [26]. The United Nations ‘Convention on the Rights of Persons with Disabilities’ [33] is an appropriate political tool to implement disabled as well as elderly persons’ full and effective participation and inclusion in society. In Article 19, it is stated that States Parties shall take effective and appropriate measures to do so by providing independent living arrangements and by fostering personal assistance [33]. Besides, the World Health Organisation’s International Classification of Functioning, Disability and Health (WHO ICF), which has been widely adopted as a biopsychosocial classification standard in the public and health care research communities transcends ideological fault lines between social and medical models and may serve as a universal system to operationalise and evaluate the implementation of policies and services. Further, it may provide opportunities to create data systems and measurable indicators of functional status, participation as well as environmental features allowing for comparisons over time, across demographic subpopulations and between nations [34, 35].

The challenges and opportunities for the governance of ageing and disability are already embedded in the context of legal frameworks, documents and policymaking processes which directly or indirectly refer to both inhomogeneous groups. The Convention is one of the major opportunities for disabled as well as elderly persons. The one-year-experience of the Austrian Monitoring Committee on the Convention suggests that the Convention in fact is a political tool to enhance political and societal will for accepting difference. Therefore, the Convention is relevant for people who are ageing with disabilities and also for the experience of disability as part of the ageing process. The Convention can be seen as forming the basis for the creation of supportive and empowering environments that meet the range of needs associated with ageing. Further, it constitutes a framework of clearly defined rights and entitlements, which would empower elderly and/or disabled persons to remove their enforced dependency and charitable status [36]. Although this will be a long way, it will mark an important step towards ‘empowered participatory governance’ [37] and would be a step towards a pro-active rather than a re-active approach concerning changing demographics. Reliance upon the commitment and capacities of ‘ordinary people’ to make sensible decisions through reasoned deliberation [37] can only work in the context of a paradigm shift towards an understanding of elderly persons as persons with equal rights. In a context where—in general—society is ageing, ‘empowered participatory governance’ will be even more important than nowadays, as the groups, which will be involved in political decision-making will differ from those presently involved. On average, people will be older and maybe more impaired. Hence, efforts to bridge knowledge between disability and ageing are both empowering and enabling—with regard to individuals, but also and mainly with regard to the ability to formulate policies for a world with changing demographics.

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