editorial

The many faces of disability in evidence for policy and practice: embracing complexity

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Background: This special issue examines the relationship between disability, evidence, and policy.
Key points: Several themes cut across the included papers. Despite the development of models of disability that recognise its socially constructed nature, dis/ableism impedes the involvement of people with disability in evidence production and use. The resultant incomplete representations of disability are biased towards its deproblematisation. Existing data often homogenise the heterogeneous. Functioning and impairment categories are used for surveys, research recruitment and policy enactments, that exclude many. Existing data may crudely evidence some systematic inequalities, but the successful and appropriate development and enactment of disability policies requires more contextual data. Categories and labels drawn from a deficit model affect social constructions of identity, and have been used socially and politically to justify the disenfranchisement of people with disability. Well rehearsed within welfare systems, this results in disempowered and devalued objects of policy, and in one Brazilian paper the systematic breakup of indigenous families. Several studies show the dangers of policy developed without evidence and impact assessments from and with the intended beneficiaries.
Conclusions and implications: There is a need to mitigate barriers to inclusive participation, to enable people with disability to collaborate as equals with other policy actors. The combined application of different policy models and ontologies, currently in tension, might better harness their respective strengths and encourage greater transparency and deliberation regarding the flaws inherent in each. Learning should be shared across minority groups.

Key words invisibility • dis/ableism • participatory • labels

This special issue examines the relationship between disability, evidence, and policy. People with disability have, since the 1700s, predominantly been evaluated in terms of a medical model (Lawrence, 1994). This positions them as deviant and non-productive

members of society, with the disability their individual fault. As such, past policies merely sought to transform them into good (that is, non-disabled) citizens, or else relegate them to the scrapheap of society. This led them to be socially stigmatised, politically marginalised, and economically disadvantaged. People with disabilities and disability scholars and advocacy groups have most recently developed their voice, particularly in the Global North, increasingly shifting the international disability agenda to one of removing social oppressions (Oliver and Barnes, 2012). Within such discourses, disability is viewed as created through environmental, social, and political barriers and not as an inevitable consequence of a biological condition (Linton, 1998). These social models of disability have resulted in a shift within policy to including people with disability in evidence production, and sometimes also in evidence use. Participatory techniques are increasingly deployed with people with disability, reflecting their transformed role as 'active citizens' (Power et al, 2013) albeit, as the papers in this special issue suggest, less so than for people without disabilities. In line with this, the basic human rights of people with disability to live dignified independent lives have been enshrined in international and national laws and statutes, most notably the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006), and referenced within new rights models of disability. The CRPD guiding principles are dignity, autonomy, choice, independence, inclusion in society, and equality of opportunity (UN, 2006). Furthermore, Article 31 of the CRPD (UN, 2006) explicitly recognises the fundamental need for more data, stating that: 'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention'. Nonetheless, disableism still thrives, that is: 'discriminatory, oppressive, or abusive behaviors arising from the belief that disabled people are inferior to others' (Miller et al, 2004: 9). Its obverse, ableism (discrimination in favour of non-disabled people) remains strong (Goodley, 2014). And while disability advocates and activists have achieved much, policymaking still falls short, and people with disabilities still often experience substandard employment, educational, community, and health outcomes.

To improve this, the disability rights movement has adopted the motto 'nothing about us, without us', advocating for participation to extend more effectively to research, so that evidence is more often made *with* people with disabilities, not *on* or *about* them (Fleischer and Zames, 2011). The movement towards greater participation is part of a broader concern about the different perspectives implicit in research, and the power of different groups such as users of services in research on these issues (Beresford, 2002; Duncan and Oliver, 2020; Maguire and Britten, 2020). However, there are many ways in which participation can be conceptualised. In a recent issue of *Evidence & Policy*, (Metz et al, 2019) considered co-creation for knowledge production as an ideal, but how well are people with disabilities represented within this and other participatory processes, and at what level? This special issue thus examines whether the most appropriate forms of evidence are used in disability policy processes; the impacts on these processes and on outcomes of using particular types of evidence; how people with disabilities currently participate in these policy processes; and how this participation can be better supported theoretically and empirically.

This is of considerable contemporary significance: disabled populations, already vulnerable, have been made more so throughout the COVID-19 pandemic (UN, 2020), which suggests their continued disenfranchisement and marginalisation in relevant policy decisions. This has sparked further calls to action by disability advocacy

groups and coalitions in the Global North (Parodi et al, 2020) and the Global South (UN, 2020). These current events and responses provide a window of opportunity (Kingdon, 1995; Guterres, 2020) to reassess and change some of the entrenched systems that consistently exclude disabled populations (Pulrang, 2020).

The papers in this special issue originate from a range of disciplines: for example, sociology, law, critical disability studies and education. Nonetheless, contributors around the world, from Brazil to Australia, have painted remarkably similar pictures. In this editorial we consider the main narrative threads under six headings of evidence production and use, and attempt to weave from them some recommendations for the future.

Making visible the invisible

People with disability are rendered invisible in policy and practice through both disableism and ableism (Wolbring, 2012). Through disableism, dismissive attitudes resulting from a lack of or inadequate data or misinformation may affect how people with disabilities are identified, defined and presented in policy (UNDESA, 2014). Through ableism, disability may not be seen as relevant to policy goals, as demonstrated for example through an analysis of the international development arena (Groce, 2011), so that relevant data are simply not collected, despite CPRD exhortations.

Priestley and Grammenos in this special issue show how these different challenges are linked and sometimes hard to tease apart (see also Goodley, 2014), in their discussion of cross–European Union (EU) use of public data on disability equality indicators, their evaluation against international human rights standards, and their impact on policy. These indicators are based on a social justice and human rights paradigm. Thus they are intended to not be dis/ableist, and should make social inequalities visible and more governable. However, their quality is often particularly weak for smaller disadvantaged groups. This can reduce their impact, for example by making them less attractive to policymakers. Priestley and Grammenos particularly show the related failings in public efforts to disaggregate, publish, and iteratively develop minority indicators. This results in gaps in the alignment of the data with evidence–based policy processes, and hence the invisibility of disability issues within these processes.

Prince similarly explores some ways that insufficient data can result in invisibility. He uses a subset of data (those of working age, 15 to 64 years) from the Canadian Survey on Disability, to draw five 'images' of disability (that is, ways of interpreting from the data) that he connects to five different models of disability. These images are, he argues, unquestioningly transmuted to cultural constructs, political activities and governmental and medical practices. What is particularly alarming about his first image, the uncounted (those not counted in the survey), is that this encompasses the most vulnerable groups, resulting in a very incomplete view of disability biased towards its deproblematisation. Prince considers this disableist and in line with Foucault's notion of subjugated knowledge: the idea that particular forms of knowledge are masked by, or excluded from, dominant institutional activities and discourses as naïve, inferior, or below the required level of scientific rigour (Foucault, 1980). Prince argues that the COVID-19 pandemic has intensified emphasis on biomedical discourses and practices, and impeded and complicated the planned transitions into education and work of people with disabilities as groups already facing precarity. But it has also made

more visible the uncounted as well as the poorly supported, and those who are afraid to disclose their disabilities. This has disrupted ableist attitudes and challenged some disableist views, potentially enabling better representation of people with disability in future political debates and policy developments in health and social care.

Current Romanian datasets on people with disabilities suffer from some of the same issues noted by Priestley and Grammenos for the EU in general. According to Petrescu and Lambru, there is a disableist focus on medical measures, disability benefits uptake and social services use for adults with disabilities, and a lack of human rights or social inclusion data or disaggregated data. Also, as Priestley and Grammenos showed, EU countries benchmark themselves against others, and Romania is no exception. The data Romania shares *externally* in Academic Network of European Disability (ANED) reports are national public administrative and EU datasets. But Petrescu and Lambru note that *within* Romania different subsets of these data are used in disability policy, depending on the public institutions involved. Therefore, EU reports for Romania do not provide full transparency. While the types of analysis undertaken by Prince and Priestley and Grammenos might thus be usefully applied to the Romanian data, Petrescu and Lambru's work also shows that analysis, such as Priestley and Grammenos have undertaken, should be augmented at the EU level by within-country analyses.

Robinson, Valentine and Idle argue that situated knowledge developed through qualitative research is an important form of evidence, that can reveal the invisible at multiple levels of policy and multiple layers of the policy process. This is because it typically involves exploration of the local lived experience, lived expertise, environments, practices, networks, and the broader political, economic and social realities of disability and its identity categories. This evidence can shift both ableist and disableist attitudes and inform future change. Similarly, Dearing describes how qualitative studies make visible those moderately to severely disabled adults who do not take part in conventional waged work, and are therefore not covered by employment legislation and datasets, representing some of the uncounted of Prince's imagery.

Good enough data?

Positivist approaches, such as administrative surveys, are often mistakenly understood to be perfect objective instruments for evidence-based policy, but both Priestley and Grammenos and Prince show this is not so. Subjective decisions include: how to define disability; how to ask questions that reflect a social rather than biomedical model of disability across different contexts; how to manage comparability across settings and cultural differences; and how to disaggregate subgroups within a diverse and intersectional population. These production and measurement choices, both authors emphasise, are shaped by political contingencies, something Robinson et al, Casanova and Widman, and Porter, Watson and Pearson also take up in this special issue. These choices lead to what Porter, Watson and Pearson call 'procedural' rather than actual objectivity.

Priestley and Grammenos discuss some potential ways of processing and presenting the methodologically weak survey data that result from such decisions, so that they are at least sufficient for basic monitoring work. In this regard, rights advocates may consider the data 'good enough' to evidence systematic inequalities for minority groups, but policymakers may worry about their technical credibility. So how can data with some in-built statistical imperfection (*stat imperfecta*) be presented to policymakers

in ways that can drive change? The key, Priestley and Grammenos say, is to support them to focus on the equality issues the data make visible (which the authors call their 'expressive function') rather than the methodology (their 'technical precision').

Prince's exposition of the different images that inadequate survey data can reinforce suggests we need to be careful to properly unpack the expressive function of survey data, so that people with disability are not represented as a homogeneous mass. He states concerns over the current disembodied aggregated nature of national social surveys and what he describes as 'their blind use as exercises in state authority'. Similarly Porter, Watson and Pearson argue that the administrative category of disability is separate from lived experience and medical knowledge, but enables the government to 'police the border between work and welfare'. While these arguments echo Priestley and Grammenos' and Petrescu and Lambru's calls for better disaggregation of survey data, for Prince and Porter, Watson and Pearson aggregation may then be not 'good enough'.

Robinson, Valentine and Idle take a similar stance. To allow local contingencies to be understood, they move beyond the social model of disability to consider, through qualitative data, the embodied enactment of disabled lives and disability support within an 'assemblage' of complexities, or intersectionalities. In this regard, they emphasise the importance of specific local networks and relationships in the everyday practice of disability and disability support, and the meaning of this for policy ontologies.

Similar considerations may be applied to the neurodiversity movement discussed by Casanova and Widman, where more severely-affected individuals are often unable to advocate for themselves within its discourses. This means their voices potentially remain unheard and subjugated and they are unable to shape the science and policy that affects them. This problem, known as 'partial representation', redolent of Prince's uncounted, suggests that within disability evidence there are different levels of subjugated knowledge.

In these accounts then, national surveys and simply measured cause-and-effect chains are perhaps 'good enough' to begin to open up deliberative spaces (as Priestley and Grammenos are able to show). But they are not sufficient for truly effective policy at the level of local policy practice or that takes account of those least likely to be heard. Evidence production for policy and practice needs to be better designed to include these excluded voices, and in the meantime, as Casanova and Widman suggest, future policy should at least reflect the missing information and take its absence into account.

Categorising disability and negotiating social constructions of identity

The knotty issue of categorising disability without over-homogenising and creating harmful stereotypes is central to the arguments of Priestley and Grammenos and Prince, as described above. A range of papers in this special issue illustrate the issues in depth, showing how categorisation and labelling affects social constructions of the identity of people with disability, thence also affecting evidence use, which voices are included in the production of evidence, and policy impacts.

Casanova and Widman, in this issue, explain for example that 'the traditional administrative breakdown of "disability" into categories of physical, intellectual, and psychiatric meant autistic individuals without intellectual impairment or major communication challenges were typically shunted towards psychiatry for treatment'.

This often failed to support their range of needs, and marginalised their voice. The recent neurodiversity movement has challenged this.

Robinson et al point out that formal participation of people with disability in policy processes tends to involve the recruitment only of those who are formally identified as such. This might be through administrative databases or through the third sector, for example. It excludes those who do not self-identify as having a disability or who have not been formally diagnosed, or do not wish to disclose a disability, or who do not fit neatly into a particular category; in other words the uncounted of Prince's analysis.

Robinson et al argue that participation in policy and practice decisions need not require formal categorisation if ableist attitudes are dismantled. They draw on data from a study of the Australian National Plan to Reduce Violence against Women and their Children. This was a study of voluntary service provision for a subgroup of women and children with disability from households where there has been domestic abuse. The mothers and children they consider were involved with Family Referral Services (FRS) because of their experiences of domestic abuse, not because of their disability. FRS staff often used person-centred approaches that did not necessitate the disclosure of disability but gave women the autonomy and space to do so within the wider context of their lives. This situated approach to understandings was therefore inclusive of those whose disability is more fluid or falls within a categorisation or identity grey zone.

Nonetheless, while women in Robinson, Valentine and Idle's case study were in control over the way their disability was named and shaped and supported by services, as subjects of policy, they found that children covered by the same services were treated as objects of policy. Disabilities were perhaps over-diagnosed in children because a formal diagnosis served as a conduit to funding and support. Thus, on the one hand, the women were being supported in the spirit of the human rights model of disability and, on the other hand, the children were supported through application of the disableist medical model. This mixture resulted from the way the policy was designed to support the relevant services, where participatory evidence from children was absent so that their entry into services had to be reduced to administrative categories. Formalised diagnosis, and the resultant imposed disability category, reduced children's agency and made them passive recipients of services and risk management: 'the need for categorisation imposed identity constraints on children that at times increased their vulnerability' (Robinson, Valentine and Idle, this issue). FRS therefore provide an example of the importance to policy of having complete representation through participatory evidence. The success of the adult service design model, informed by qualitative research evidence on both service needs and barriers to service use such as categorisation and labelling, sits uncomfortably with the problematic child service provision arising from the lack of such evidence.

Several papers in this special issue focus on the way such labels as 'deviant' and 'undeserving' have been used socially and politically to justify the disenfranchisement of people with disability (for example, Porter, Watson and Pearson; De Sales Lima, Moreira Jacinto and Arantes Faria; Dearing), and the exclusion of their evidence.

Dearing's, Petrescu and Lambru's, and Porter, Watson and Pearson's analyses centre on the political use of the rhetoric of waged work as denoting good or deserving citizenship (non-dependency), and as being central to a normal life. Prince describes something similar as emerging from the Canadian survey data. Dearing focuses on the treatment of those with an intellectual disability (ID) in UK disability employment

policy. She describes how a model that predominantly relied on the use of sheltered workshops was replaced by one that privileged individualised employment support. This marked a shift from segregation towards open employment with its discourses of inclusion, civil and legal rights and choice. But it was shaped by disableist biomedical measures of function, capacity, and psychological determinants of the prospects of good citizenship as an employed person. Dearing discusses how those with a moderate to severe ID were more likely to have been employed within the sheltered workshops because of the lack of opportunity for or access to other work. The change in policy means they have been pushed into alternatives such as internships, where token nominal sums are constructed as financial remuneration and 'paid work'. But unlike waged work this is not covered by legislation. This 'flexploitation' (Ross, 2009), Dearing argues, is morally dubious within the paradox of a disability policy positioning employment as the best form of social inclusion, yet failing to ensure provision for inclusive employment.

Porter, Watson and Pearson describe the assault on identity often felt by people being assessed for disability benefits and work capacity according to the deficit-focused medical model. Casanova and Widman argue this is because syndromes and conditions that involve the brain and behaviour affect some of the most intimate aspects of a person's sense of self. Similarly, Casanova and Widman say, since most disabilities occur within a biological gradient or spectrum, the many people with disabilities who fall into the grey zones may be seen as inauthentic. This was a significant theme in Porter, Watson and Pearson's study, with the exclusion of these disabilities being designed into the policy itself. Decontextualised measures of functioning, promoted as objective and hence valid, reliable and fair (misleadingly so, as this special issue shows), were adopted on the back of the rhetoric of a 'culture of dependency' and benefit claimants as 'shirkers and scroungers'. This then was a values-based decision driven by political contingencies. Porter, Watson and Pearson consider the objectivity thus achieved as procedural objectivity, with assessments of functioning being flawed proxy indicators of disability. Claimants themselves talk of personal medical testimony as the 'real evidence' and that produced by the commercial assessors as inauthentic, detached and lacking an understanding of the physiological, psychological and social circumstances that together result in a dynamic continuum of functioning.

These qualitative studies illustrate how dissatisfaction of people with disabilities with policies and services is often rooted in disableist experiences that are perceived as disempowering, dehumanising, and devaluing. This disenfranchisement can lead to a form of Foucauldian self-policing (Foucault, 1975; Foucault, 1979), with 'identity politics' resulting in an 'oppressor versus oppressed' mentality. Porter, Watson and Pearson's data and Casanova and Widman's practice-based discussion both highlight this. Casanova and Widman suggest that practitioners and policymakers may also take on the role of the oppressed when criticised by disability movements for their adherence to the medical model, further silencing those with disability. Porter, Watson and Pearson's analysis gives an empirical example.

De Sales Lima, Moreira Jacinto and Arantes Faria's analysis very powerfully further highlights the harm that can be done when particular social constructions of identity are used that are not shaped through evidence from the intended beneficiaries of policies themselves. In their case study, in Mato Grosso do Sul, Brazil, the failure to do so, and the choice to adopt mistaken cultural norms, resulted in harmful non-government organisation (NGO) interpretations and operationalisations that

served to harmfully reproduce and even increase existing inequalities and prejudices. Specifically, the principles of the best interests and rights to family and community life of indigenous children with disability were ironically used as justification for violating these same rights. The indigenous children they considered, who had all been in hospital with disabling conditions, were moved by the NGO from hospital either to institutional foster care for a long period or to non-indigenous substitute families through formal adoption processes. All the children therefore experienced broken family and community ties. This policy developed from a false belief that indigenous people were not competent to care for children with disabilities, a social identity construction that developed from an anti-indigenous political and social context and not from evidence itself. Moreover, structural challenges, and a lack of cultural expertise among the street-level bureaucrats (Lipsky, 1980), meant they could absolve themselves of responsibility for their actions. These authors argue for the importance of inter-institutional cooperation and intersectoral dialogue, in which indigenous people participate, for the formulation and implementation of more culturally appropriate public policies. Benefits might include the production of relevant qualitative and quantitative evidence, the instrumentalisation of intersectoral options and policies matched to the needs of the beneficiaries, and greater adherence by those working on the ground to the guidelines and principles enshrined within the policies.

Political contingencies and impact assessments

The point of social policies is to deal with problems of societal origin that are a threat to the values and dominant interests of a society, and that can be potentially alleviated or solved (Jamrozik and Nocella, 1998). So far we have shown that, with regard to disability policies, the potential beneficiaries may also be falsely perceived as the threat to society. This can lead to undesirable policy outcomes for those with disability. Policy decision makers have a legal obligation to take this into account given that the social and human rights perspectives are enshrined in global statute and law. This requires impact and evaluation assessments (W.K. Kellogg Foundation, 1998; Patton, 2011), but these are often de-prioritised in policy processes.

Petrescu and Lambru describe how, within Romania, the national employment system collects data about people with disabilities who receive training, counselling or labour mediation, but there are no data regarding job subsidies or personalised social support for young people with disabilities. The lack of a comprehensive needs assessment and impact dataset has reduced the quality of the Romanian disability strategy and the design of policy measures in this area. Petrescu and Lambru consider how, when Romanian employment policies for people with disabilities were developed in 2006, these drew on a social model of disability. This, they point out, was politically contingent on Romania's accession to the EU. The policymakers used evidence from sheltered workshops, civil society organisations (CSOs) and civil society networks. Petrescu and Lambru's own research with these groups revealed that at the time all they could draw on were comparative impact studies of models from other EU countries, combined with some informal insights of their own practices. This law was modified in 2017 to the potential disadvantage of those with disability, pushing them to state benefits rather than assisted employment. The authorities justified this decision through a medical model-informed analysis of unspecified data on the number of sheltered workshops and their commercial activities, proportions of employees with disabilities,

and employer disability quotas achieved. The impact on socioeconomic integration was never formally analysed, though a requirement of the law. Representatives of sheltered workshops whom Petrescu and Lambru interviewed stated that they had offered impact evidence in 2017 but that it was not considered in the final decision.

Dearing's impact data on the open employment policy for adults with an ID show the benefits may depend on the severity of ID. Policy impact analyses, Dearing argues, would give policymakers the knowledge needed to extend the legislation that covers formal waged work to include the community-based 'work-like' activity that people with more severe ID often do. Porter, Watson and Pearson, like Dearing, draw from a UK setting for their analysis of assessments for disability benefits and work capacity. They argue that assessment reforms have been driven by an ideal of method (Priestley and Grammenos' 'technical precision'), when it is the product of inquiry – the impact – that matters most.

Meltzer et al consider the absence of the disabled voice from policy evaluations of market stewardship. Several countries have individualised welfare budgets and devolved purchasing to people with disability, who can then make individual choices about what supports to obtain from an available market of services run by government. Such quasi-markets do not operate like conventional markets, and market stewardship is needed to 'guide and steer' them towards an appropriate balance between market efficiencies and policy equity objectives. Meltzer et al point out that current evaluations of these schemes focus only on simple inputs (such as number of providers), but do not consider the level and quality of benefits and the needs fulfilment obtained from bought services, even though that is a stated aim of individual funding schemes.

Supporting inclusion and evidence to action

Ultimately, as the papers in this issue have shown, decision makers use many kinds of evidence across the policy process, but this use is influenced by the values, ideologies, political implications, and budgetary and other resource impacts that are brought to the policy table, as well as the power of the different policy actors and the prevailing contexts. This can lead to a tension between the drivers of performance management and the demand for a rigorous, more objective evidence base on the one hand, and pressure from non-governmental actors for transparency, accountability, and a participatory approach on the other hand. Here, Robinson, Valentine and Idle specifically note the many barriers to non-tokenistic participation of those with disabilities, shaped through epistemological and power hierarchies regarding what knowledge matters, who gets to speak, and who is listening. Robinson et al describe the most common extant form of participation as knowledge transfer, which they define as the sharing with policy decision makers of 'lived expertise', rather than the more commonly used and more marginalising term 'lived experience'.

Knowledge transfer is commonly manifest through advisory bodies or formalised service user participation settings, and encompasses what Petrescu and Lambru and Priestley and Grammenos term advocacy work. It also includes variations of co-design (Metz et al, 2019), though co-production (Metz et al, 2019) may perhaps be seen more as collective decision making than knowledge exchange. These different types of citizen participation are becoming increasingly embedded in policy in many countries, including Australia (Metz et al, 2019), where Robinson, Valentine and Idle are based. Often it is not the citizens themselves but their representatives, such

1 as disability organisations and advocates, who participate, however. Participation by
2 people with disability in most forums requires, Robinson, Valentine and Idle point
3 out, critical and inclusive methods that are often not deployed.
4   Barriers to meaningful participation include disableist cultures of discrimination
5 and low expectations (which at best reduce contributions to narratives of experience
6 rather than expertise), access and accessibility barriers, and the need to include
7 structural support, opportunity, appropriate information and resources, and skill
8 development. Robinson, Valentine and Idle suggest the phenomenon of evidence-
9 making interventions (EMI) as a theoretical framework for enhanced participatory
10 processes. This recognises that policy implementation and evidence are shaped by,
11 and can only be understood through, local and specific contexts.
12   Meltzer et al meanwhile suggest a more practical framework to support policy
13 actors to include lived experience as part of the evidence. Their framework draws
14 on inclusive, participatory and action research, and particularly addresses access and
15 accessibility barriers. Accessibility is important to ensure inclusivity across a range
16 of disabilities and needs, and to avoid a narrow conceptualisation of what counts as
17 evidence. Meltzer et al's framework also stresses the need to amplify the voices of
18 people with disability by empowering them to take an active role, so that policymakers,
19 service providers, and other policy actors respond to what people with disability
20 actually say they need, not what it is perceived they need. These suggestions are
21 similar to recommendations for the greater inclusion of other marginalised groups
22 in evidence production and use for policy (Farooqi et al, 2018).
23   Even when the right evidence is produced, it needs to be translated into action to
24 be useful. The engagement between the use of research and its production is a two-
25 way process with demand (pull) and production (push). As we have seen, the use of
26 research on disability is influenced by the perspectives (theoretical and ideological
27 assumptions and priorities) of both policymakers and researchers, thus affecting
28 both the push and pull sides of the equation. The issue then is how different actors,
29 including researchers, behave and thus influence these evidence ecosystems (Gough
30 et al, 2019). Papers in this issue provide examples of some possibilities.
31   Priestley and Grammenos undertook collaborative advocacy work with European
32 Commission civil servants. This led to their successful mainstreaming of disability
33 equality measures from surveys into EU generic and disability-specific policy processes.
34 Policymakers across the EU then used the survey evidence to push for better disability
35 data, benchmarking their own country against others.
36   Petrescu and Lambru undertook research specifically to inform advocacy work to
37 push to amend policy. They used multiple approaches to demonstrate the negative
38 impact of relevant policy on the socioeconomic inclusion of people with disabilities.
39 The findings were discussed with local and national decision makers, civil society
40 organisations, companies and trade unions. This resulted in a positive change to the
41 relevant disability policy in 2020. Thus, like Priestley and Grammenos, Petrescu and
42 Lambru were able to show that advocacy involving a collaboration between researchers
43 and others may be sufficient to result in policy revisions.
44   De Sales Lima, Moreira Jacinto and Arantes Faria's analysis, like Petrescu and Lambru,
45 and Priestley and Grammenos, shows the importance of multi-actor collaborations,
46 but also highlights the complexities and difficulties of advocacy and other forms
47 of representation of marginalised voices (DeSantis, 2010). Their situational analysis
48 of the NGO policy-driven breakup of indigenous families with children with

disabilities reveals that the indigenous peoples were not passive victims, but created specific deliberative spaces, such as an intercommunity assembly, to get their voices heard. These produced important and useful evidence, but this was initially ignored. Once federal government actors were involved, more attention was given to those indigenous children's policy actors who had previously been unsuccessful in competing for space in local decision-making arenas, such as university researchers, members of the indigenous deliberative arenas, and civil servants.

Giordono, in her practice paper, suggests that disability-focused programme or advocacy groups should explicitly adopt an appropriate policy-process framework to work out which evidence production to prioritise in planning, initiative development and dissemination. This would support further work along the lines of what Petrescu and Lambru achieved. Whereas Meltzer et al develop a framework to drive the use of evidence in policy, thus *for* policy, Giordono shows how existing frameworks can be used to better understand the use of evidence in policy processes, hence *of* policy. For example, the Social Construction Framework (SCF) (Barbehön, 2020) can be used to explain how social constructions of people with disability interact with political power through four social categories ('advantaged', 'dependents', 'contenders' and 'deviants'). This can support predictions of policy welfare and support allocation. It can also show how such allocations are likely to shift in the event of a shift in social understandings of disability identity, as promulgated by Prince among others in this issue.

A toolbox of approaches

Just as the collaboration of a range of policy actors is important to disability policy, so is the use of a combination of approaches to their theoretical underpinnings. Thus, for example, in her practice paper, Giordono demonstrates how the variety of theoretical and epistemological bases to the different policy process frameworks means there are suitable matches across the corresponding variety of models of disability.

The greatest focus in this special issue has been on the tensions between the medical and social or human rights models. Prince, and Casanova and Widman in their practice paper, consider that a composite approach might be more helpful, with each model useful for a particular purpose. Only their combined application will fully depict and then connect the micro phenomena of everyday lived realities to macro level social structures and state policies, and the relevant connecting social networks (Prince, this issue). This can lead to expanded spaces for democratic engagement and public accountability of decision makers.

Casanova and Widman argue that some of the tensions, discussed by Porter, Watson and Pearson and Dearing for example, arise because of a failure by policymakers to contextualise the different models. Thus, while the medical model is useful in framing our understanding of human illness, Porter, Watson and Pearson, Priestley and Grammenos, and Prince show that its perceived objectivity is exaggerated. Manifestations of its use, such as administrative surveys and welfare assessments, fail to recognise it as a cultural construct founded on classicism, racism, sexism, liberalism and ableism (see Casanova and Widman, Porter, Watson and Pearson, and Dearing for example). Instead of being used as a categorical tool with limitations, the medical model is then mistaken for its patho-anatomical correlates, in other words taken as a faithful and objective representation of disability itself. Prince's and Porter, Watson and Pearson's papers were developed largely because of concerns regarding this. But

if this potential trap is understood and guarded against, then the types of evidence it produces may still have value.

Casanova and Widman also tackle some issues with the use of social and rights-based models. For example, these models have sought to remove the stigma associated with disability, but in their application – such as by the person-first movement – they are sometimes considered instead to increase this by marginalising a person's lived experience of their disability. The neurodiversity model is an example of a disability rights model borne out of autistic concerns with such application of the social model. Importantly, it has given a strong voice to many people with autism, but it too has also generated debates, in this case concerning partial representation.

Casanova and Widman conclude by proposing the Biological Gradient Model which simply intends to promote a 'Goldilocks' approach: one that uses aspects of the medical, social, neurodiversity, and other disability models that are 'just right' for the policy problem at hand. In other words, this both draws from their combined strengths rather than introducing alternative epistemologies, and pushes for simultaneous consideration of the weaknesses of each. Thus it could be expected to result in the appropriate production and use of scientific and medical evidence that is methodologically balanced by epistemologies that exclude negative deficit judgments, rather than sitting in tension with them. It would, for example, mean that people with disabling conditions are not considered as deviant or amoral citizens when their condition does not improve, or if they ascribe to conditions such as neurodiversity and hence do not aim to be 'repaired'. The toolbox approach would mean they are therefore culturally accepted, but at the same time have a voice in policy processes that improve access to the necessary supports they need to live fulfilled lives. And it would mean that policymakers can draw on approaches in ways that should be more acceptable to all.

So what does this mean for disability policy and practice moving forward?

Overall, this collection highlights many problems with the forms of evidence used in policy processes for disability issues, and the participation by people with disabilities in policy-process evidence production and use. People with disabilities are frequently marginalised and excluded from these. Many groups, such as those with ID, may be entirely missing within existing datasets and therefore absent within policy itself. Levels of participation in policy processes result, both in terms of the particular voices that are present and the degree to which they are included or treated as experts in their own lives.

Technical and values issues at the international and national level, and sometimes unclarified selective use of evidence, feed down into less than sufficient, or tensioned, practice decisions on the ground. Objectivity can take on a life of its own or it can be harnessed by policy decision makers procedurally, based on political and economic contingencies, in ways that at times can be perceived as morally dubious or as falling outside of current UN frameworks and legislation. People with disability are often treated as a homogeneous mass that overrepresents those with the greatest voices and fails to appreciate the gradations of impact that policies will have; one size does not fit all. This often results in a blind use of partially representative data, the othering of many people with disabilities or their total exclusion and invisibility, and outcomes

that can sometimes harm, particularly those subgroups who are less well represented in the data or for whom contextualisations are ignored.

It is evident from the activities of the different disability movements, and the inconsistent or juxtaposed use of a variety of different models of disability within and across policy fields and processes, that disability policymaking may be considered an especially complex endeavour (Cairney, 2013). Particularly debated within the disability policy field are the specific framings of disability and non-disability, and the influence of this on evidence production and use in policy and practice. Much research, and not just the papers included in this special issue, suggests that the medical model still holds sway in many social and institutional settings. Greater use of other models can shift the policymaker gaze from the individual to structural modes of oppression (Oliver, 1996). The ontologies and epistemologies on which policymaking practices are based therefore have a considerable effect in shaping the associated policies.

So how can the participation of those with disabilities be better supported theoretically and empirically? We started this discussion above. We wish to make some further points here, some of which are suggested by this collection but not evidenced within.

1. There needs to be more transparency about the methodological imperfections inherent in different datasets and forms of data, without lessening the importance of their 'expressive function'. Priestley and Grammanos provide some starting suggestions on how this might work.
2. Multiple forms of evidence are needed to form a composite picture. Context is important, yet when editing this issue we were surprised by the degree to which qualitative and ethnographic data are underused in disability policy.
3. A two-pronged approach is important – the inclusion of people with disability in evidence production and use, and their consideration within policy – the push and the pull working in tandem. Frameworks grounded in one or more theories and models of policymaking, such as suggested in this special issue, can help to ensure that key considerations are made.
4. Multiple policy actors, including those with disability, should collaborate to develop policies that are more appropriate and workable across systems by negotiating behaviours, decisions and actions (Langer et al, 2016). Features of complex policy systems should be considered, such as the interactive, iterative relationship between the development of policy and existing practices, and the values and politics on which they are based. Without this approach, many subgroups of people with disabilities will likely remain largely 'othered' in policy, and much policy will be badly thought-out and implemented.
5. What it means to have a disability is often improperly understood. Qualitative data can provide insights but will only represent those who can take part. Data collection needs improving across ontologies, to better represent those subgroups currently excluded. This includes better recognition in policymaking and policy use of the fluid, dynamic nature of many disabilities and diagnosis grey zones, and the avoidance of procedures that treat the accounts of people with disabilities as inauthentic or less valid. Their evidence should be considered to represent expertise as well as experience, so that it is not silenced or deprioritised by others who claim greater epistemic authority by virtue of their professional role.

AQ2

6. A broader non-ableist approach to inclusion may be appropriate in some cases. For example, in policymaking in general, where disability is not a focus, mechanisms should nonetheless be incorporated that provide a space for people with disability to have the choice if and when to open up about their disability-specific expertise.

7. Recommendations and frameworks relevant to other marginalised groups such as ethnic minorities should be consulted; there are lessons to be learned across groups, given the many similarities between them in the concern for visibility; evidence production; categorisations of difference; expectations around authenticity; credibility; capabilities; and the capacity for inclusion. Studies in health, for example, may not include particular minority groups (Redwood and Gill, 2013; Treweek et al, 2020), or may be based on males alone even when the condition affects people regardless of gender (Ravindran et al, 2020). Systems and processes are being developed in health to address equity issues in experimental evaluations that can provide learning for policy (Welch et al, 2017). Intersectional analyses are needed to appreciate how these different identities interact and converge to create discrimination or privilege in different contexts, and in turn how they impact on the various forms of their inclusion in policy processes.

8. We should concentrate on harnessing strengths and assets in disability policy. Defining groups in terms of deficits, several papers in this collection show, leads to their exploitation or harm. The development of medical devices, science and technology has increased the potential for social participation by people regardless of disability. Strengths-based approaches are also central to the principles of respect for the human rights of people with disabilities, and their potential for important contributions. It is important for an assets-based approach not to result in blind integration and micro-exclusion (Cologon and Thomas, 2014), something made evident in Dearing's paper (this issue) and which can lead to 'othering' in both implicit and explicit ways (Cologon and Thomas, 2014).

9. This collection has also shown – in keeping with a systems approach – the dynamic effect of external influences on the ways that evidence is used in disability policy, and the degree to which participatory work is incorporated or rejected. Austerity measures can result in a pull to the medical model, and global activism or vested interests (such as Romania's desire to join the EU, see Petrescu and Lambru, this issue) can pull towards the social or human rights approach. Using Casanova and Widman's Goldilocks model to operationalise inclusivity within policy processes therefore seems wise.

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The authors declare that there is no conflict of interest.

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