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ARTICLE

An ambivalent approach to disability in older age: evidence from reporting by states parties under the UN Convention on the Rights of Persons with Disabilities

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Abstract

Issues of 'disability' and 'ageing' are usually approached separately in theorising, activism and policy making. Yet people with disabilities age and many people will experience disability if they live long enough. Human rights approaches to disability enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD) are not often applied to older people experiencing disability. This article presents findings of a systematic qualitative analysis of reports made by 28 European states to the UN Committee on the Rights of Persons with Disabilities, the independent body that monitors CRPD implementation, focusing particularly on Article 19 CRPD ('Living independently and being included in the community'). While states' reports refer to older people or ageing in different contexts, their approach can be characterised as ambivalent. Reports tend to constitute older people experiencing disability as 'older' rather than 'disabled'; they do not demonstrate a thorough engagement with disability experienced in older age, and display a limited focus on people ageing with lifelong disability. Several reports detail exclusions of 'older people' from disability supports to live in the community and some exclude impairments associated with ageing from definitions of what 'disability' is. The reports provide almost no evidence of consultation with organisations working on ageing. The article concludes that while the CRPD's potential to contribute to realising rights for older people with disabilities is under-recognised among scholars and non-governmental organisations, the fact that states refer to older people in their reporting under the CRPD provides a starting point for more engagement.

Keywords: ageing and disability; article 19 CRPD; human rights convention on the rights of persons with disabilities; independent living

Introduction

Issues of 'disability' and 'ageing' are usually approached separately in theorising, activism and policy making. This is paradoxical given that people with disabilities age and that many people will experience disability if they live long enough. One consequence of siloed thinking on ageing and disability is that human rights approaches to disability, brought forward particularly by the UN Convention on the Rights of Persons with Disabilities (CRPD), tend not to be applied to disability experienced in older age (Devandas-Aguilar 2019). The CRPD instituted a 'paradigm shift' within approaches to disability generally, which involves moving from perceptions of people with disabilities[1] as 'objects' of charity, from the medical model, towards viewing people with disabilities as holders of rights (European Network of National Human Rights Institutions (ENNHRI) 2016a; Quinn 2009). However, as the former UN Special Rapporteur on the Rights of Persons with Disabilities highlights, the rights of older people experiencing disability (or with long-term care needs) are not always perceived to be encompassed within the CRPD's provisions, and older people with disabilities are, instead, perceived as 'mere beneficiaries of care and welfare' (Devandas-Aguilar 2019, 7).

At the outset, it is important to note that ageing is not synonymous with disability. But it is undeniable that disability rates increase with age. In EU-27, almost 52 per cent of people aged 65+ experienced disability in 2023 (that is, reporting 'some' or 'severe' levels), while some 75 per cent of people aged 85+ did so (Eurostat 2024). Thus, the likelihood of experiencing disability increases as we age, and numbers of people worldwide aged 80 and over are predicted to triple between 2020 and 2050 (WHO 2022). The EU Statistics on Income and Living Conditions (SILC) survey suggests that people aged 65+ constitute about 48 per cent of the total population of adults with disabilities in EU-27 (that is, of people aged 16+), and it is notable that the SILC survey does not include people living in institutions/retirement homes, who are estimated to number over 2 million people aged 65+ (Grammenos 2021). Thus, population ageing means that older people constitute a large and increasing proportion of people experiencing disability. Notwithstanding this, as Priestley (2002) noted, concerns about implications of demographic ageing result in surprisingly few linkages with parallel debates over disability rights and policies among policy makers and activists. Scholarship exploring the ageing–disability nexus is still surprisingly limited (Aubrecht et al. 2020).

The CRPD does not include a provision specifically addressing rights of older people with disabilities or engage with challenges at intersections of ageing and disability (Devandas-Aguilar 2019; Naue and Kroll 2010). However, it *is* relevant to disability experienced at any point of the lifespan even if not widely applied to older people experiencing impairment (Devandas-Aguilar 2019, 7). The European Network of National Human Rights Institutions (ENNHRI 2016a) is among the bodies highlighting that older people with disabilities often don't have access to a range of long-term care services that allow them to live in their own homes/communities. This is despite the provisions of Article 19 CRPD ('Living independently and being included in the community'), the first international treaty provision to explicitly provide the right to community living for people with disabilities (ENNHRI 2016a). Furthermore, the great majority of recipients of long-term care in the EU are older people, most of them women (Social Protection Committee and European Commission 2014). ENNHRI (2016a) advocates for greater recognition by stakeholders of the relevance to older people with disabilities of the CRPD and, specifically, of Article 19. But fragmentation of policies on disability and on ageing results in invisibility of experiences of disability in later life; human rights violations against older people with disabilities are often not categorised as such (Devandas-Aguilar 2019). However, the CRPD represents an opportunity to strengthen a rights-based approach to disability experienced in older age (Devandas-Aguilar 2019).

It must also be said that disability experiences are diverse – people experiencing disability in older age are not a homogenous group. People with disabilities are living longer and a significant demographic shift is taking place among them (Molton and Ordway 2019). Thus, populations living with disability in older age include people who have aged with lifelong or long-standing disability (who tend to be referred to as people 'ageing with disability') as well as people who have lived relatively disability free until reaching mid-life or late-life (referred to as experiencing 'disability with ageing') (Verbrugge and Yang 2002). People ageing with disability sometimes experience secondary conditions and more rapid ageing (LaPlante 2014; Verbrugge et al. 2017) and they can age with a legacy of disadvantage such as high unemployment levels, low levels of marriage/cohabiting, and low incomes and educational attainment (see Iezzoni 2014; Macdonald et al. 2018; United Nations 2018). For Bickenbach (2021), every human being is either ageing into disability or ageing with disability.

Against that backdrop, this article discusses whether, and in what ways, countries that are parties to the CRPD (states parties) engage with issues of disability experienced in older age in their reporting under the CRPD. The article reports on a qualitative document analysis of states' reports to the UN Committee on the Rights of Persons with Disabilities (CRPD Committee), focusing on 28 European countries and especially on the right to live independently in the community enshrined in Article 19 CRPD. It first sets the scene by expanding on some issues touched upon already – considering implications of siloed approaches to disability and ageing, referring to ageing within human rights frameworks and outlining key features of the CRPD. After that, it outlines the methods undertaken and presents and discusses the findings. The analysis suggests that reports of states parties refer to issues of ageing in different contexts, although in ways that can be somewhat ambivalent.

Background

Siloed approaches to disability and ageing

Undergirding these issues is the fact that older people with impairments tend not to be regarded as 'disabled' in the same way as children or younger adults might be, as impairment tends to be considered a social norm of ageing (Priestley 2002, 2006). Indeed, the very definitions of what 'disability' is differ within approaches to ageing and to disability. 'Disability' in older age is usually seen in medicalised or functional terms, typically as inability to perform certain routine actions or in terms of 'frailty' (see, among others, BURDIS 2004; Verbrugge and Yang 2002). A consequence is that broader cultural and social-structural influences are overlooked in explanatory frameworks for disablement in older age (Kelley-Moore 2010) and limited attention focuses on subjective experiences of disablement processes in older age (Leahy 2021). By contrast, in the context of disability generally, following the articulation of social models of disability decades ago, all definitions or models informing scholarship and activism reject a view of disability as the *sole* result of individual differences or biology. Instead 'disability' is linked to a range of contextual factors – cultural, social, economic and political (see, among others, Goodley 2011; Oliver 1990, 1996; Shakespeare 2021).

Public policy frameworks on disability and on ageing tend to remain separate. Typically, policy approaches to ageing are based on a medical model, sometimes involving 'custodial' care, while approaches to disability have evolved towards a social care model (Monahan and Wolf 2014, S1). Thus, in general terms, disability policies encompass social aims and aims of independence (Monahan and Wolf 2014), but older people experiencing disability can be ineligible for supports such as disability-related grants or rehabilitation services (Devandas-Aguilar 2019). Competing ideologies and languages, complexity and illogicality are associated with these separate administrative categories on disability and on ageing and with transitions between them in several countries (see Coyle and Mutchler 2017; Era 2021; Jönson and Larsson 2009; Leahy 2018; Molton and Ordway 2019; Priestley and Rabiee 2001; Putnam 2007). For example, a tendency is identified to define older people with disabilities as 'elderly' rather than 'disabled', and not to treat them as if they have the same rights to support as their younger peers (Jönson and Larsson 2009; Leahy 2018; Mastin and Priestley 2011). When we look to the EU, the Green Paper on Ageing (European Commission 2021a) includes references to disability experienced in older age, as does the EU Disability Strategy (albeit to a very limited extent) (European Commission 2021b), but policies and initiatives on long-term care tend to be approached separately (Georgantzi 2023; see Social Protection Committee and European Commission 2014; OECD/European Commission 2013). In several European countries, supports to live independently in the community, such as personal assistance, are limited to people of working age or are available only to older people who have been receiving them prior to age 65 (European Network on Independent Living (ENIL) 2013,[2] 2018). Human rights concerns are also highlighted in respect of quality of long-term care available to older people in their homes (Equality and Human Rights Commission 2011) and in residential settings (ENNHRI 2017).

Furthermore, policies are not well developed across many countries for people ageing with disability (Bigby 2002; Carter Anand et al. 2012; Raymond et al. 2014). Transferring from one service category to another due to chronological ageing can mean that 'the orientation of services shifts from supporting independence to reproducing dependence' (Walker and Walker 1998, 127) and there can be fears that control/choice will diminish within services for 'older' people (Putnam 2007, 2017). The phenomenon of more people ageing with disability, therefore, challenges different sectors to intersect more.

When we turn to consider disability scholarship and activism, the focus tends to be people with disabilities of working age and children (Priestley 2006). Connections between forms of discrimination associated with being older and being disabled are slow to emerge and very limited attention has been paid to people who acquire impairments with ageing or even to people ageing with disability (Thomas and Milligan 2018). Simultaneously, 'positive' ageing discourses shape how people growing older think about ageing (Estes et al. 2003; Pack et al. 2019). These discourses risk constructing experiences of disability in older age as a personal failure and can contribute to exclusion of people who do not fit the 'positive' model (Kahana and Kahana 2017; Larsson and Jönson 2018; McGrath et al. 2016). In this context, ideas of 'normal ageing' have come to be associated with maintaining norms of self-care aimed at delaying or denying 'decline' (Higgs et al. 2009, 703), and efforts to counter ageism involve dissociating older age from illness, impairment and dependency (Larsson and Jönson 2018). Thus, scholarship on ageing engages with 'disability' largely as an 'undesirable condition' to be 'limited in scope and compressed in time' (Kahana and Kahana 2017, 5), and civil society organisations working on ageing often identify with 'active ageing' rather than with disability issues or as organisations of people with disabilities.[3]

Human rights and older people

The efficacy of adopting a human rights approach to disability in older age is starting to be recognised, especially in respect of experiences of dementia (Aubrecht and Keefe 2016; Dementia Alliance International 2016; Shakespeare et al. 2019; Thomas and Milligan 2018) and some countries have developed/updated dementia strategies to become more strongly rights-based (Cahill 2022). Human rights perspectives that engage with the CRPD are also emerging in debates on care of older people (see Birtha et al. 2019; Morrison-Dayan 2023; Steele et al. 2020). Furthermore, in recent years, European umbrella organisations among ageing and disability movements highlight that older people with disabilities cannot access certain services or may face discrimination on grounds of age when accessing services. For example, ENIL (2013, 2018) notes several countries where availability of personal assistance is subject to age-ceilings, and AGE Platform Europe (2017, 2019) identifies countries where laws and policies impose age limits on access to disability benefits, mobility allowances or personal assistance.

The consequences of siloed approaches to ageing and disability continue, including how age-sector organisations are rarely consulted by national governments on the CRPD or on developing disability policies. In fact, in a position paper on Article 19 CRPD, AGE Platform Europe (n.d.) reports findings from a survey amongst its members that a majority were not involved in implementing/monitoring the CRPD in their countries and some were not aware of its existence. Alongside this, discussions of shortcomings in the human rights framework for older people are increasingly prominent. Thus, while existing human rights standards address universal rights of all individuals, including older people, no distinct international convention specifically addresses rights of older people (Birtha et al. 2019). The UN Open-Ended Working Group on Ageing is considering the possibility of a new UN convention on the rights of older people (that is, one addressing ageing in broad terms). Bodies like AGE Platform Europe and ENNHRI have advanced this discourse (Birtha et al. 2019). Progress has, however, been slow in progressing the Working Group's mandate (ENNHRI 2022) and the Office of the High Commissioner for Human Rights (2021) suggests that the Covid-19 pandemic has highlighted the urgency of improving international human rights frameworks for older people.

This article does not engage with arguments about the proposed Convention on the Rights of Older Persons, but focuses on the CRPD, whose provisions come closest at present among human rights instruments to providing a legal framework to protect the rights of older people with disabilities (or older people termed as having impairments or care/support needs) (Birtha et al. 2019). A starting point is that, despite challenges, the CRPD has potential to contribute to realising rights for older people with disabilities that is under-recognised within approaches to ageing among scholars and non-governmental organisations (NGOs). As ENNHRI (2016a) highlights, we need greater recognition of the relevance of Article 19 CRPD ('Living independently and being included in the community') to older people with disabilities by all stakeholders, and greater investment by governments in developing community-based services.

Relevant features of the CRPD

This section outlines key features of the CRPD, starting with its definition of 'disability'. The CRPD conceptualises disability as resulting from 'the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (Preamble, para. 5 and Article 1 CRPD). In this respect, the CRPD is said to embrace a social-contextual model of disability (Broderick 2015; Broderick and Ferri 2019). The CRPD is also said to embed a human rights model of disability, emphasising human dignity and valuing impairments as part of human diversity (Degener 2016, 2017).

The CRPD is viewed as uniquely inclusive by comparison with other human rights treaties – emphasising participation of people with disabilities in developing domestic laws, policies and practices (Arstein-Kerslake et al. 2020). Related provisions are found in Article 3 and also, inter alia, under rules on implementation and monitoring the CRPD (Articles 4 and 33). Article 4(3) requires consultation and active involvement of people with disabilities, through representative organisations, in developing and implementing the CRPD and in 'other decision-making processes concerning issues relating to persons with disabilities'. In guidelines, the CRPD Committee (2018, para. 11) suggests that 'representative organisations' are those governed and led by people with disabilities who are to compose a clear majority of their membership. Article 4(3) specifically refers to 'children with disabilities' but does not specify other groups such as older people.[4] Article 33 deals with implementation and requires that 'Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process' (Art. 33(3)). Article 33(3) CRPD, therefore, while highlighting again the participation of representative organisations of persons with disabilities, also anticipates broader civil society engagement in implementation. Furthermore, guidelines issued by the CRPD Committee addressing participation in its work also refer many times to 'civil society organizations', who are welcome to make written submissions that contribute to the review of states parties' reports (CRPD Committee 2014, Annex II).

States that have ratified the CRPD are required by Article 19 to 'recognize the equal right of all persons with disabilities to live in the community, with choices equal to others', and to take 'measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'. Realisation of this right requires structural change, including de-institutionalisation, according to the CRPD Committee (2017, para. 41). The CRPD Committee (2017, para. 8) states that the right to independent living 'refers to all persons with disabilities, irrespective of … age', and guidelines issued in respect of de-institutionalisation state that 'efforts should include older persons with disabilities, including those with dementia' (CRPD 2022, para. 52). Civil society organisations have lobbied governments to end the institutionalisation of people with disabilities and support independent living, often focusing on younger people with disabilities, even though many older people prefer to remain in their own homes and even though many care settings display characteristics of institutions (ENNHRI 2017). Thus, efforts made to support people with disabilities to transition to community-based care may not be seen as relevant for older people, and more attention is required to be paid to the relevance of Article 19 to older people with disabilities (ENNHRI 2016a, 2016b).

Methods

This article, which forms part of a broader research project called DANCING that applies a multi-method approach (see 'Financial support' at the end of the article), is based on data gathered from an analysis of reports available on the UN Treaty Body Database. The reports in question are progress reports made to the CRPD Committee, the body of independent experts that monitors implementation of disability rights in countries that have ratified the CRPD. States parties are required to submit reports at intervals on how rights and obligations are being implemented, based on which the CRPD Committee notes concerns and makes recommendations. Civil society organisations and representatives of organisations of people with disabilities can input into that work by way of written submissions (or shadow reports) addressing the national situation in their countries (see CRPD Committee 2014).

The study relates to 27 EU member states plus the United Kingdom. This scope reflects the fact that this article is part of a larger EU-wide project and also that the UK was a member of the EU during much of the timeframe considered, which makes it interesting to consider issues emerging in the UK along with those emerging in other European countries. The study encompasses the 40 reports made by those countries to the CRPD Committee (cut-off date mid-June 2023). The reports were filed over the years 2010 to 2022. They consisted of initial reports from all 28 countries and additional, subsequent reports from 12 of those countries (usually combined second and third reports). When referring to reports of states parties, the article gives the unique document symbol or classifier assigned to it in the CRPD reporting process, which enables identification of each specific report and the relevant country. Each symbol refers to the instrument (CRPD), the CRPD Committee (C), the country (using recognised country codes) and the number of the report (typically, 1 or 2–3). For example, the classifier CRPD/C/AUT/1 refers to the first report from Austria made to the CRPD Committee.

This study involved conducting a systematic document review, adopting a thematic qualitative approach to document analysis and seeking to ascertain what references to older people with disabilities suggest about how disability in older age is understood and approached. The author searched each entire document for words related to ageing (which included 'old*', 'elder*', 'aged', 'ageing/aging', 'retire*', 'senior', 'dementia/Alzheimer's' and 'age 60/65'). Based on a review of the results of that initial search, and informed by arguments discussed already, the analysis focused on some sections that were particularly relevant and that illustrate how issues to do with ageing tend to be apprehended in reporting. Thus, the analysis engaged in detail with sections in each report that addressed Article 19 on living in the community, those providing definitions of disability (often set out in response to Articles 1–4) and those addressing consultative processes (often included in response to Articles 4 and 33).

Thematic analysis involves examining the data, summarising it and drawing out key points by identifying recurrent themes (Tight 2019) or identifying repeated patterns of meaning (Braun and Clarke 2006). Thus, following coding, the author developed themes that identified patterns (Bowen 2009; Braun and Clarke 2006; Coffey 2013). There are some preliminary things to note in relation to the reports reviewed. A key issue is that even 'official' records must be approached not so much as firm evidence of what they report but in light of what they are used to accomplish (Coffey 2013), which, in the case of the reports reviewed, is to evidence compliance by governments with the provisions of the CRPD. Typically, the reports refer to a broad array of measures and it is difficult to tell how their implementation operates in practice. Instead, what it is possible to engage with is the meaning of the documents and their contribution to the issues being explored (Bowen 2009).

Findings

References to ageing or older people feature in parts of the reports addressing different articles of the CRPD. In other words, the tendency not to treat older people with impairments as 'disabled', and the lack of engagement with the CRPD by age-sector NGOs, does not prevent framers of the reports from including issues to do with older people with disabilities, albeit typically not referring to them as such. The terms used tended to be 'old/er', 'elderly' or 'retired' people. The text search across the documents suggested that such references occur in a range of contexts, including in the context of care/support to live at home (Article 19), a key focus of this article. However, they also occur in other sections of reports, including those addressing health or health insurance (Article 25); housing (sometimes under Article 9); risk management (often in relation to Article 11); and legal issues, including voting, exercise of capacity and access to justice (referenced in different contexts, including in respect of Articles 12, 13 and 29). There were also cursory references to age in the context of equality or non-discrimination legislation (often relating to Article 5). Also, what is omitted is interesting. For example, older women tend not to feature in sections addressing gender in response to Article 6 ('Women with disabilities').

There is, however, a very inconsistent approach across reports as to the extent to which issues to do with ageing or older people are referenced. As will be illustrated in the discussion of the findings, the text of many reports is marked by ambivalence as to how disability in older age is apprehended, often including references to 'older people', on the one hand, but also sometimes excluding impairments associated with ageing from the category 'disabled', on the other, and/or referring to age-ceilings applied to supports available in some cases.

In the remainder of this section, the following five themes, identified by way of the systematic document review undertaken, are discussed: (1) mixed picture relative to ageing in definitions of disability; (2) services/programmes support living at home but tacit acceptance of institutionalisation for older people with disabilities; (3) exclusions of older people with disabilities from services/supports; (4) limited attention paid to people ageing with long-standing disability; and (5) lack of consultation with NGOs on ageing.

Mixed picture relative to ageing in definitions of disability

Fundamental issues are not clearly addressed in reports, starting from the fact that they tend not to define the terms used to address issues of ageing. It is often unclear if, when they talk about 'disabled people' or 'people with disabilities', that is meant to include older people with disabilities. However, reports frequently refer to 'older people' (or cognate terms such as 'elderly' or 'retired') alongside 'disabled people' (or cognate terms like persons/people with 'disability/disabilities' or 'special needs'), which suggests that a distinction is made – in other words, older people with disabilities are apprehended as 'older' rather than 'disabled', consistent with research findings (Jönson and Larsson 2009; Leahy 2018). Thus, reports rarely specify that they are addressing the situation of older people with disabilities, although that is implied by the fact that there are any references to 'older' people at all in reports made under the CRPD. Reports tend not to distinguish between the two groups mentioned already – people ageing with disability or people experiencing disability with ageing. Reports also sometimes refer to people experiencing dementia, reflecting perhaps dementia advocacy invoking the CRPD (see, among others, Dementia Alliance International 2016). This also begs the question as to why only that experience of impairment in older age is specifically highlighted.

Reports reviewed often address 'disability' definitions in laws/policies in their countries in opening sections, typically addressing Articles 1–4 CRPD. From the point of view of ageing, there was a mixed picture in terms of whether definitions encompass older people with disabilities or whether they seek to exclude them. It was common for definitions of 'disability' not to include any specific reference to ageing, consequently not making it explicit if older people with disabilities were understood as included. Some reports propound definitions that explicitly *include* older people (among them CRPD/C/LV/2–3, para. 9; CRPD/C/LTU/1, para. 7; and CRPD/C/EST/1, para. 9). It was also commonplace for reports to refer to several definitions used in different contexts or under different laws/policies. Definitions used in the context of employment could define disability with regard to capacity to work, sometimes specifying an upper age limit (or 'retirement age') in this context (see, among others, CRPD/C/AUT/1, paras. 17, 20; CRPD/C/EST/1, para. 10; CRPD/C/ITA/1, para. 3; CRPD/C/LTU/1, para. 9).

These were not the only definitions that involved exclusions on age grounds; some other definitions explicitly exclude disabilities linked to ageing. Among these, for example, reports from Austria reference definitions excluding people with 'age-related' impairments (CRPD/C/AUT/1, para. 21; CRPD/C/AUT/2–3, para. 35). Thus, a reference is made to a law which states that 'persons with impairments are those who, due to the failure of important functions as a result of physical, mental, intellectual or multiple such (*not predominantly age-related*) impairments, are lastingly and significantly disabled in an important social context' (CRPD/C/AUT/1, para. 21, emphasis added).

Other reports include definitions of disability by reference to activities considered normal, appropriate or typical for a given age – a somewhat ambiguous formulation but one that may attempt to exclude disability experienced in older age or suggest tacit acceptance of lower levels of ambition in terms of functioning or support at older ages. For example, this is how a law defining disability is referred to in a report from Croatia (CRPD/C/HRV/1, para. 10): 'a person with disability is a person with a permanent limitation, reduction or lack of capability to perform some physical activity or psychological function *appropriate for his/her age*, arisen as a consequence of health impairment' (emphasis added).

Similarly, a Swedish report (CRPD/C/SWE/1, para. 14) refers to legislation whose target group is defined as persons 'with other permanent physical or mental disability that is obviously not due to normal ageing'. A German report (CRPD/C/DEU/1, para. 15) refers to deviations from functioning 'typical for their age' and a report from Belgium (CRPD/C/BEL/1, para. 9) refers to disability as limiting/preventing the fulfilment 'of a role usual for a person's age' (see also CRPD/C/CYP/1, para. 20; and CRPD/C/POL/1, para. 3).

Somewhat related to the issue of disability definition, reports cite statistics as to population levels of people with disabilities or numbers availing of certain services. Typically, these reports cite overall numbers of people with disabilities without stating if that includes older age-groups. Some statistics cited, however, draw on particular reports or surveys that exclude people above certain ages (see CRPD/C/CYP/1, para. 22). On the other hand, there are several reports that specify that statistics cited *include* older people with disabilities (among them CRPD/C/EST/1, para. 11; CRPD/C/HRV/1, para. 4; CRPD/C/LV/2–3, para. 19; and CRPD/C/SWE/1, para. 10). For example, the initial report from Sweden (CRPD/C/SWE/1, para. 10) refers to using 'an approximate definition' and to there being 'between 1.1 and 1.5 million persons of all ages with disabilities of varying degrees'.

Overall, therefore, a mixed, and sometimes ambivalent, picture emerges, with some definitions of disability in use whose effect seems to be to exclude age-related conditions, and, therefore, many older people experiencing impairment, from the category 'disabled'. At least in some contexts, reports appear to construct impairments as a natural and 'normal' part of older age. It is perhaps ironic, and emblematic of the siloed approaches within different fields, that in this context it appears that impairment is considered to be part of 'normal' ageing and, thus, not 'disability', while in scholarship on ageing, 'normal ageing' is associated with distancing from disability, or denial of 'decline' (Higgs et al. 2009, 703).

Services/programmes support living at home but tacit acceptance of institutionalisation for older people with disabilities

The second theme concerns how reports address care and supports to live at home, specifically relating to Article 19. There were reports whose sections addressing Article 19 did not refer to any issues to do with older people or ageing. Among them are reports from Cyprus (CRPD/C/CYP/1), Hungary (CRPD/C/HUN/1), Malta (CRPD/C/MLT/1), Portugal (CRPD/C/PRT/1), Romania (CRPD/C/ROU/1), Slovakia (CRPD/C/SVK/2–3), Spain (CRPD/C/ESP/1) and the UK (RPD/C/GBR/1). There are others whose sections addressing Article 19 refer to ageing/older people in very limited terms (see, among others, CRPD/C/BEL/1, but see para. 190; CRPD/C/EST/1, but see para. 122; and CRPD/C/SVK/1) and still others that refer to programmes of support targeted specifically at 'older' people (see *e.g.,* CRPD/C/HRV/1, para. 102). It is impossible, however, to know whether – even where a report contained no specific mention of older people in addressing Article 19 – the references to 'disabled people' (and cognate terms) are meant to encompass older people with disabilities. Also, as already mentioned, reports tend not to clarify if they are referring to people ageing with disability or to people first experiencing disability with ageing.

Reports that engage specifically with issues of ageing in respect of Article 19 typically do so by outlining actions taken or planned to support 'older people' (or cognate terms) or people with dementia to live at home, referring to laws, policies or programmes, often alongside services provided to 'disabled people' (or cognate terms). This could encompass a range of items such as care and support, home help or personal assistance, housing arrangements and community supports such as centres, education or training. There were many examples. Among them, the Greek report (CRPD/C/GRC/1) contains several references to older people (or cognate terms) in the context of Article 19 alongside references to 'disabled people' (or cognate terms). One paragraph refers to 'independent living', stating that 'This action aims at safeguarding *independent living conditions for elderly and disabled people at their homes*, in order to ensure their stay in a familiar physical and social environment, avoid referral to closed care structures and prevent social exclusion' (para. 167, emphasis added, see also paras. 163–166, 169). Other examples (*i.e.* of references to services available to 'older people' and to 'people with disabilities') are found in the following reports, among others: CRPD/C/AUT/1, para. 180 and others; CRPD/C/BGR/1, paras. 97, 99 and others; CRPD/C/CZE/1, paras. 182, 187 and others; CRPD/C/DEU/1, paras. 149, 151; CRPD/C/DNK/1, para. 170; CRPD/C/FRA/1, paras. 164, 170, 173 and others; CRPD/C/ITA/1, paras. 59, 65; CRPD/C/LVA/1, para. 183; CRPD/C/SVN/1, paras. 91–92, 100. However, on the whole, these statements can be quite brief and tend to be couched in quite general terms. It is impossible to glean whether different criteria or service models apply to people experiencing disability in older age, but several reports (discussed later) refer to services/supports from which 'older people' are excluded.

There are some specific references to services designed (or planned) to prevent institutionalisation of older people with disabilities (see *e.g.,* CRPD/C/LVA/1, para. 18; CRPD/C/NLD/1, para. 192) and this is explicit or implied in the many reports that reference supports to live at home for older people just discussed. However, a report from Denmark was notable in including a reference to 'older persons' in the context of closure of institutions, stating:[5] 'As the main rule, all social housing offers intended for older persons and persons with disabilities can include this group [severe disabilities]. Since 1988, it has not been possible to establish nursing homes and "protected homes" because they are considered institutions' (CRPD/C/DNK/QPR/2–3, para. 161).

By contrast, some discussions of de-institutionalisation focus on people with disabilities below an age-ceiling (typically age 65 or 'pensionable age'), referring to younger people with disabilities living in nursing homes or institutions and to steps taken, or to be taken, to cease this practice. See, for example, the Irish report (CRPD/C/IRL/1, para. 235), and the second–third Belgian report. The latter (translated from French) states: 'Unfortunately, the German-speaking Community notes that an increasing number of *disabled people who have not reached pensionable age* are obliged to go and live in a nursing and care home in order to benefit from appropriate follow-up' (CRPD/C/BEL/2–3, in response to Question 18(b), emphasis added).

While de-institutionalisation is an understandable focus for younger age-groups, it is arguable that there is tacit acceptance that it is not necessary for people above certain age thresholds, tantamount to acceptance that older people with disabilities are not entitled to the rights enshrined in Article 19 to have a choice to live in the community. Furthermore, some reports specifically characterise institutions by reference to older age. For example, the initial report from Austria (CRPD/C/AUT/1, para. 200) includes an implicit acknowledgement that services for older people remain framed in different terms, citing criticism from a disability NGO to the effect that de-institutionalisation is not being progressed and that there is an 'excessive orientation towards a paradigm of care and help for the aged'. Overall, therefore, reports can display tacit acceptance that institutionalisation involves a type of care appropriate to long-term care of older people.

Exclusions of older people with disabilities from services/supports

It was not common to find a specific focus on issues arising due to the traditional separation of services on disability and ageing, although there are examples of explicit exclusions of older people with disabilities from services available to other people with disabilities, which represents the third theme. Instances of upper age-limits are cited as applied in access to health screening or supports for working (see *e.g.*, CRPD/C/DNK/QPR/2–3, para. 201; CRPD/C/HUN/1, paras. 187–189; CRPD/C/HUN/2–3, paras. 240–241), but the focus here is on exclusions from supports to live at home. These are found in reports from Austria (CRPD/C/AUT/2–3, para. 284), Denmark (CRPD/C/DNK/1, para. 323), Finland (CRPD/C/FIN/1, paras. 216, 363), France (CRPD/C/FRA/1, para. 164) and Sweden (CRPD/C/SWE/1, para. 151). For example, a report from Sweden (CRPD/C/SWE/1, para. 151) refers to a social reform from 1994 that included legislation to 'guarantee good living conditions for persons with extensive and permanent disabilities'. The paragraph specifies those entitled to access this, which includes 'persons with other permanent physical or mental disabilities *that are obviously not due to normal ageing*'[6] (emphasis added). Thus, ideas of 'normal ageing' are invoked to exclude older people with disabilities from access. This 'reform' has already been highlighted by Jönson and Larsson (2009) for its institutionalised ageism and how this constructs significant impairments among older people as a 'natural' part of older age rather than 'disability', while people of the same age who experience impairments before they turn 65 are provided with a different type of support (Larsson and Jönson 2018). In an instance of the ambivalence embedded within reports, the initial report from Sweden is, nonetheless, one of those that *includes* older people with disabilities in the statistics it cites referring to 'persons of all ages with disabilities' (CRPD/C/SWE/1, para. 10), as discussed already.

Other reports evidence similar exclusions of age-related disability in access to personal assistance. These include approaches taken in reports from Austria (CRPD/C/AUT/2–3, para. 284) and Finland (CRPD/C/FIN/1, para. 216). For example, the Finnish report states: 'In the organisation of personal assistance, a person is considered as having a severe disability if … [they] need assistance from another person in order to manage daily life functions at home and away from home. *Persons whose need is mainly due to ageing-related illnesses and disabilities do not qualify for personal assistance*' (CRPD/C/FIN/1, para. 216, emphasis added). Era (2021) confirms that Finnish legislation excludes people from availing of personal assistance if their service needs mainly stem from age-related disabilities, but not specifically from other disability services, although extending this exclusion to all disability services is under consideration.

The initial report from Denmark (CRPD/C/DNK/1) in dealing with Article 28 ('Adequate standard of living and social protection') refers to local councils being required to cover additional expenses of daily life but only for people 'between the age of 18 and old-age pension age' (para. 323). A report from France (CRPD/C/FRA/1, para. 164) also suggests exclusions of older people, referring to 'Institutions and services for persons aged between 20 and 59' which are said to include a very broad range of services.[7] Indeed, France is among the countries identified by AGE Platform Europe (2019) where different schemes operate for 'disabled' people and for 'older' people.

This discussion of explicit exclusions of older people with disabilities from supports to live at home, which are said to be available to other people with disabilities, should not be taken to imply that the countries mentioned are the only ones that operate them in practice, given the age limits on supports for independent living already highlighted (ENIL 2013, 2018; see also AGE Platform Europe 2019). Neither does it facilitate cross-country comparison in terms of quality/adequacy of what is provided. As Jönson and Norberg (2023, 151, 163) argue, discussing the situation in Sweden, while legal discourse communicates 'ageist notions', older people excluded from disability services still receive home care and nursing home care that in international comparison 'would likely be regarded as generous'.

However, the examples identified *do* suggest that a narrower range of services can be targeted at older people with disabilities with exclusions framed by way of recourse to the notion of impairments due to 'normal ageing' or 'age-related' conditions, concepts that occur also in definitions of disability, discussed earlier. As Era (2021) argues, for an older person, an impairment may be interpreted as age-related until proven otherwise. Overall, this represents, this author suggests, unsatisfactory and ageist ways of dealing with the issues at stake. This is not least because timing of disability onset may determine rights to support for older people of the same age, or two people of different ages with similar needs and rights to support may be treated differently.

Limited attention paid to people ageing with long-standing disability

There was a paucity of attention given to the situation of, or the rights of, people ageing with disability (*i.e.* people who are now older having lived with disability over the long term), discussed by way of the fourth theme. One area where there often *was* an explicit focus on this group related to access to pensions (responding to Article 28 'Adequate standard of living and social protection') by reference to transitions to retirement pensions or access to pensions before the usual retirement age (see, among others, CRPD/C/HRV/1, para. 212; CRPD/C/DNK/1, paras. 449, 498; CRPD/C/DEU/1, para. 234; CRPD/C/LVA/1, paras. 325, 330; CRPD/C/ESP/1, paras. 194, 200–202).

However, there was little focus on whether/how the situation of this group is addressed within health and care policy frameworks on disability, on whether they are entitled to the same range of supports to live at home as younger people with disabilities (under Article 19), and on whether they are required to transition to services for 'older people' at a given chronological age. In a few cases, references that existed focused on one group among them – people ageing with intellectual disability ('ID'). It must also be acknowledged, given the lack of clarity around terms used in reports, that it is possible that some other references to 'older people' (and cognate terms) are intended to include this group without that being made explicit, or they may be included in general references to 'people with disabilities' without that being made clear. This makes analysis challenging and underlines the importance of states parties defining the terms used relative to older people with disabilities.

The German report represents a rare usage of the term 'older persons with disabilities' (responding to Article 23 CRPD 'Respect for home and the family'). It seems likely that this is intended to relate to people ageing with disability: 'The right to live a self-determined life also applies to older persons with disabilities … Advice services on conversions appropriate to age are being expanded, networked and professionalised. Existing programmes are being continued. Networks and services can facilitate both independence and participation in the life of society' (CRPD/C/DEU/1, para. 186). The references here to programmes focused on 'participation in the life of society' can be said to carry through the more socially orientated aims enshrined within policy frameworks on disability rather than adopting the narrow/medicalised approaches to care associated with policy frameworks on ageing.

A report from Spain (CRPD/C/ESP/2–3) suggests a similar approach (see also Austrian report CRPD/C/AUT/2–3, para. 304(b)), referring to people with ID ageing prematurely and to programmes promoting personal autonomy and active ageing: 'With regard to the promotion of personal autonomy and independent living, in residential and non-residential centres alike there are programmes to promote personal autonomy and active ageing, since persons with intellectual disabilities often age prematurely' (CRPD/C/ESP/2–3, para. 157).

Only a few other reports explicitly reference supports for people ageing with disability, but these tend to be quite cursory references, sometimes documenting numbers benefiting from particular schemes. For example, the Finnish report refers to growth in access to personal assistance among recipients aged 65+ and lists numbers of people with ID aged over 65 accessing services, including assisted housing (CRPD/C/FIN/1, para. 221, Annex 8; see also report from Lithuania, CRPD/C/LTU/2–3, para. 158). A French report (CRPD/C/FRA/1) references 'independent accommodation for persons with disabilities, especially older persons' (para. 173; see also para. 249). Finally, a few reports reference war veterans, who might be assumed to constitute a group ageing with disability, suggesting that there can be special arrangements for them.

Overall, although references do exist to supports to live at home for people ageing with disability under Article 19, these are infrequent. As mentioned, ENIL (2013, 2018) documents age-ceilings in access to supports to live independently, and this can involve different levels of service after a given age, or even distinguishing in determining supports between conditions due to ageing and those due to existing disability (ENIL 2013[8]; see also Larsson and Jönson 2018). Overall, lack of attention to the situation of people ageing with disability is a striking – and perhaps surprising – feature of many reports.

Lack of consultation with NGOs on ageing

Consultation is claimed to be extensive in reports, but a striking lack of consultation with groups working on ageing is evident. This illustrates ambivalence at the heart of how states parties address issues of disability in older age – including references to 'older people' in some contexts, yet not consulting specifically on ageing and disability. Thus, the reports reviewed almost universally refer to consultation and input by people with disabilities and their representative bodies in policy-making processes and in monitoring the CRPD (usually addressing Articles 4(3) and 33). The degree to which representatives of age organisations are *not* involved in consultative processes becomes especially evident in reports that name a plethora of national NGOs consulted without any organisations that, on the face of it, work on ageing. An example comes from a report from Hungary (CRPD/C/HUN/2–3, para. 5) that lists 68 NGO members of a monitoring group in an Appendix – none of which appears to be an age-sector organisation. In a Slovakian report (CRPD/C/SVK/1, para. 5), more than 30 bodies (including ministries, human rights organisations, trade union and employer representatives) are said to have been consulted in the preparation of the report. None appears to be primarily working on issues of ageing.[9] It is possible that some of these organisations – such as human rights bodies, social partner representatives or disability NGOs – may in fact raise issues of ageing and disability. However, that cannot be assumed, given the siloed approaches that operate; nor can it be assumed that issues concerning both people ageing with disability and people first experiencing disability with ageing would be raised.

Any references to organisations representing older people were extremely minor. For example, an Italian report (CRPD/C/ITA/1, para. 215) refers to consultation with unions 'representing workers, pensioners and employers'. A UK report references one age-sector organisation (AGE UK) among 24 entities that identified issues relating to implementing the CRPD (CRPD/C/GBR/1, para. 351; Annex III), but in Annex II that report references consultation with 46 organisations, none of which appears to be an age-sector organisation. Nonetheless, that report (Annex III) involves a rare reference to an age-sector organisation in the reports reviewed. The paradoxical nature of this becomes apparent when one considers that older people are by far the largest group of social care users in the UK (Woolham et al. 2017; see also Mastin and Priestly 2011).

Given the large and growing proportion of people with disabilities constituted by older people (see Grammenos 2021), lack of consultation with NGOs in the age-sector appears as almost a perverse omission, even if we understand some of the legal, socio-cultural and political reasons for it. These include the relative weakness of ageing advocacy networks compared with disability networks (Sciubba 2016) and the fact that organisations working on ageing do not typically identify as representatives of organisations of 'people with disabilities' (a classification foregrounded in consultation processes enshrined in the CRPD's Articles 4(3) and 33).

Discussion

This article reports on a study examining how European countries address disability in older age in reporting to the CRPD Committee, focusing particularly on Article 19 CRPD, which concerns living independently and being included in the community. The study evidences references in many reports to older people or to ageing, occurring in connection with a variety of rights articulated in the CRPD, albeit often as quite cursory references and in inconsistent ways. A tendency in reports to refer to 'older people' (and cognate terms) alongside 'disabled people' (and cognate terms) suggests that a distinction is made between the two.

Several reports detail exclusions of 'older people' from general disability supports and also from definitions of what 'disability' is by reference to 'age-related' conditions or 'normal' ageing. Thus, reports sometimes seek to distinguish 'disability' from impairments experienced in older age – with older people with disabilities appearing at times as less deserving of a range of supports. In short, older people with disabilities are not always considered entitled to the full rights enshrined in Article 19 to have a choice to live in the community, with evidence of acceptance of a narrower focus in services for them in some reports and some evidence of acceptance of continued institutionalisation for that group. These instances amount to institutional ageism (see Palmore 2005) and reflect how age-based differentiations are often considered necessary and unproblematic (Georgantzi 2023). It is also likely that anticipated costs of doing otherwise are influential factors in decisions taken (see Jönson and Norberg 2023; Mastin and Priestley 2011). This would be consistent with Lloyd's argument (2012, 1) that the overarching principles informing how population ageing is approached in countries with established welfare states involve promoting active ageing to prolong independence in later life, and a 'tight rein' on care spending to contain costs.

Focusing on the situation of people ageing with lifelong or long-standing disability, the analysis suggests a paucity of explicit engagement – a striking omission, given the legacy of disadvantage that many are likely to experience in older age. However, a few references to them in the context of supports to live at home seem to carry over a more socially orientated approach to disability policy frameworks in general. More detailed analyses would be possible if reports clarified what groups are meant in all contexts. This could be recommended by the CRPD Committee, which could explicitly refer to the situation of older people with disabilities in reporting guidelines (including people ageing with long-standing disability and people first experiencing disability with ageing).

This is because there is little evidence that states parties are being challenged to any extent on the ambivalence evident in their approaches, and reports provide almost no evidence of consultation with organisations working on ageing in relation to the CRPD or in respect of disability policies. Reasons for this situation have been touched upon already, including a 'strong counter-tendency' within movements on ageing and on disability, with older people's organisations typically advocating for 'active ageing' and distancing from issues of 'decline' or disability, and disability activism often prioritising issues relevant to younger people (see Priestley 2002, 368; Thomas and Milligan 2018; Walker and Walker 1998). It is also possible that, for disability activists, addressing ageing risks shifting focus from the rights of people currently considered 'disabled', although that does not entirely explain limited engagement on behalf of people who have aged with long-standing disability. This author suggests that there is a basis for states to consult with age-sector organisations not least because of references to 'civil society' organisations in Article 33(3) CRPD (addressing participation in monitoring). The related guidelines on inputting into the work of the CRPD Committee (2014) also provide a basis for civil society organisations working on ageing to submit shadow reports.

As stated at the outset, amongst international human rights instruments the CRPD comes closest at present to providing a legal framework for protecting the rights of older people with disabilities (Birtha et al. 2019). The fact that states parties do address issues affecting older people with disabilities in their reporting under the CRPD represents a starting point. This article suggests that opportunities are being missed, however, to assert the rights of older people with disabilities through lack of a thoroughgoing engagement with these mechanisms by representatives of older people in each country, limited engagement with disability experienced in older age by disability NGOs, and limited liaison between the two sectors. The findings point towards the need for more coalition-building.

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Notes

1. In this article I use the term 'people/persons with disabilities' consistent with the human rights model of disability enshrined in the CRPD, while acknowledging also that terminology remains contested, and that 'disabled people' is often used to highlight disability due to environmental and societal barriers.
2. A survey with experts from 22 countries published by ENIL in 2013 found that 16 countries offered personal assistance services at that time, but eight of them excluded people above certain age thresholds (typically age 65). The countries were Belgium, Denmark, France, Iceland, Ireland, Slovakia, Slovenia and Sweden. Among them, four operated provisions for including older people *if* disability assessment had occurred prior to the age-ceiling (Belgium, France, Slovakia and Sweden) (ENIL 2013).
3. Underlying this issue is how people who experience disability first in older age do not typically identify as 'disabled' even when otherwise categorised as such (Darling and Heckert 2010), although there is empirical evidence suggesting that that can shift through, inter alia, contact with disability activism (Leahy 2023).
4. The CRPD does, however, contain several references to age or older persons, including in Articles 8, 13, 16, 25 and 28.
5. According to WHO (2019), Denmark is the only EU country where construction of traditional old-age and nursing institutions has been banned, and large institutions with multiple-bed rooms are replaced with homes in which users have individual living spaces.
6. It, thus, repeats what that report had already stated in addressing definitions of disability and discussed already (CRPD/C/SWE/1, para. 14).
7. These include social support services; a medico-social support service for adults with disabilities; home nursing services; medical care homes; and special care homes, shelters and residential homes (CRPD/C/FRA/1, para. 164).

8. In Belgium (Wallonia) people aged 65+ could get personal assistance in some cases if recorded with the relevant agency (AWIPH) before age 65 *and* if the impairment was linked with initial disability, *not* age (ENIL 2013).

9. A subsequent report from Slovakia (CRPD/C/SVK/2-3, para. 53) references consultation with 'non-governmental organisations [that] provide assistance to seniors and persons with disabilities', in relation to a specific issue – developing a plan on adult guardianship, that is, not by way of input into implementing the CRPD or development of disability policies more generally.

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