Crystallising the Case for Deinstitutionalisation:

COVID-19 and the Experiences of Persons with Disabilities

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ACKNOWLEDGMENTS

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This Report is about home. It is as simple – and as powerful – as that.

Home is where we form our sense of self – the very stuff of our identity. We do so in close association with others. Home is also the material expression of self – a sort of scaffolding that holds us together. In our homes we see ourselves reflected back – even in the small things like a flower vase or a family picture. It is quintessentially private. And yet home is also public. Our front doors beckon others in. Outside, we engage with the community – neighbours, shopkeepers, bus drivers. They are part of who we are. Living life my way and in the community is the very essence of independent living. And home is a crucial enabler for this to happen.

And home is exactly what is denied to large segments of the population.

Quite rightly, the authors of this Report take an intersectional view. The lack of 'home' damages children, persons with disabilities, older persons and others.

Institutionalisation represents an extreme form of segregation – so extreme that it self-evidently amounts to unconscionable discrimination. Even if Article 19 of the UN convention on the rights of persons didn't exist (right to live independently and be included in the community) it would have to be inferred from the prohibition on discrimination and extreme segregation.

Yet entire systems have somehow rationalised institutionalization as an appropriate response to human difference, as cost effective and as an efficient way of delivering care and services. It is none of the above. This Report helps to counteract these false narratives.

Humanity is at an inflection point. Because we take seriously the promise of independent living for persons with disabilities we must take deinstitutionalisation seriously. Because we take intersectionality seriously we have to explore why institutional options still remain for children and older persons and to find way to change the narrative and our expectations. This Report continues the conversation and keeps it moving in the right direction. It contains a clear set of Conclusions and Recommendations that, if followed, would help steer systems away from congregated options and toward more community-based solutions. Maybe in time we will see this digression toward institutions as a historical accident – something rooted in an outdated conception of welfare dating back to the mid-20th century. The 21st century points in a radically different direction. This Report gives courage to those who seek change. It is an important part of a deeper conversation on the need for, and the possibilities of, a new and wider policy imagination for all our citizens.

Catalina Devandas Aguilar

Formerly UN Special Rapporteur on the Rights of Persons with Disabilities

The COVID-19 Pandemic has exponentially exposed the structural failures of our policy responses. The disproportionate levels of infections and deaths among persons living in institutions raised alarms all around the world from the early stages of the health crisis. We commissioned this report from LSE to bring together up-to-date information on the adverse consequences

of living in institutions and how they were further compounded by COVID-19. I greatly welcome this report. It presents an opportunity for governments to use its findings and recommendations to transition to community-based services, and to ensure that all persons with disabilities are able to choose where and how they live, with the support they need.

EXECUTIVE SUMMARY

INTRODUCTION

Millions of persons with disabilities, children and older persons live in congregate settings. Whilst the motivation for providing such care may be well-intentioned, that is not always the case. Many of those settings are 'institutional', with residents denied autonomy and choice, provided with poor quality health and social care, and experiencing social isolation, neglect or abuse. The COVID-19 pandemic has highlighted many of those failings, whilst at the same time exposing residents to disproportionate risks of infection, severe illness and premature death.

We were invited by the former United Nations Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, to conduct research to address the following four questions:

- What is the situation today in relation to institutionalisation of persons with disabilities and older persons?
- What has been the impact of COVID-19 on institutional care? How have governments responded?
- What are the arguments for deinstitutionalisation?
- What policy and other measures can be and are being taken to shift the balance of support from institutional care to community-based services?

In this report, we summarise the evidence and experiences of persons living in congregate settings in general, and in terms of the impact of COVID-19, to understand the barriers to deinstitutionalisation, and to highlight the approaches that have sought to overcome those barriers. We consider all disabilities and long-term conditions that might lead to institutionalisation, for all age groups across the world.

LIVING IN CONGREGATE SETTINGS

The UN Convention on the Rights of Persons with Disabilities (CRPD) outlines the rights of persons with disabilities and the obligations of Member States to promote and protect all human rights and fundamental freedoms of all persons with disabilities. While not all older persons have disabilities or impairments, many of the CRPD articles are relevant to all older persons; they also represent a significant proportion of persons living in congregate settings.

Although many countries have ratified the CRPD and other policies related to deinstitutionalisation, millions of persons around the world continue to experience (a) institutionalised lives and (b) inadequate care. For example, between 5 million and 6 million -children live in congregate settings, despite over 80% having a living parent. Unsurprisingly, children with disabilities represent a large proportion of these children in institutional settings.

Congregate care remains a main form of provision for adults with disabilities in many countries, and the number of persons placed in congregate settings is rising in some regions of the world. There are, for example, still around 1.5 million persons of all ages living in congregate settings in 27 EU countries. Furthermore, as the world population ages, with associated growth in the numbers of older persons needing health and social care support, some countries are experiencing growing demand for care and services.

An Ad Hoc Expert Group set up by the European Commission defined 'institutional culture' as follows:

> Residents are isolated from the broader community and/or compelled to live together; … do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the residents' individualised needs.
>
> (European Commission 2009, p.9)

Given the abundance of evidence about how institutions blight the lives of the individuals who live in them, it is both astounding and scandalous how many persons with disabilities and older persons live in settings of this kind.

The CRPD states that all persons have the right to live independently and to be included in the community, to choose their place of residence and with whom they live, and to live in dignity. Rights to liberty and freedom of movement are also fundamental human rights; however, many forms of deprivation of liberty based on disability are common, as are restriction of legal capacity, involuntary hospitalisation and institutionalisation.

All persons have fundamental legal capacity, and their preferences should be central to decisions about their own welfare, even in situations when they need support for making decisions. Some older persons may not be able to express their wishes about where they would like to live, for example because of advancing dementia, and others may need to make those decisions based on a best interpretation of their will and preferences. But older persons living in congregate settings are often denied their rights to independence and autonomy, with few opportunities to make personal decisions or exercise choice or control over their lives. Visiting restrictions policies have also highlighted the lack of rights of the relatives of individuals who live in congregate settings.

Advance care planning can support autonomy and accommodate preferences for future care if a person is expected to not be in a position to communicate in a way that others cannot interpret in future. In addition, older persons living in congregate settings face multiple difficulties, including higher rates of loneliness and lower quality of life compared with persons living in the community. Some studies show public policy and cost advantages that support human rights obligations to support individuals to live independently in the community. Cost comparisons between congregate and community settings are not straightforward, for example, because of differences in the needs and other characteristics of individuals who live there. Overall, the majority of older persons

experience better health, rights, and quality of life when support is provided in the community.

Children are particularly vulnerable as they usually have no power to make decisions about their lives and are dependent on others in terms of choice and autonomy. Children have the right to grow up in a family, and institutions – regardless of size or quality – are not adequate substitutes for family-based care. The CRPD emphasises equal rights of children with disabilities, including that States must provide alternative care within the wider family or within the community in a family setting.

Quality of care for children living in congregate settings is often poor and they are at risk of neglect, abuse or exploitation. However, even when their basic needs are met, institutions cannot provide sufficient social and cognitive input for children's adequate physical, cognitive or socio-emotional development. Despite this evidence and current human rights standards, congregate living is still the first choice of alternative care for children in many countries, and large proportions of public funding are committed to institutions for persons of all ages. Furthermore, studies suggest that savings generated by closing institutions would be sufficient for supporting children to live in family-based care.

Persons with disabilities experience many forms of stigma, discrimination and marginalisation, including limited access to services and life opportunities. Persons with intellectual disabilities or persons with psychosocial disabilities receive poor quality care in many countries, and their fundamental human rights are often violated and abused, including the right to freedom, education and employment, citizenship, and health care. Residents spend their lives segregated from society in closed hospitals or similar institutions, often in very remote locations, some abandoned by their families. They often experience neglect and abuse, and many are forcefully detained, tortured or treated without consent.

Comparisons of community-based services with congregate living for persons with psychosocial or intellectual disabilities have

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consistently shown better outcomes, for example, in terms of health, quality of life, vocational rehabilitation, self-management and autonomy. A majority of persons strongly prefer living in community rather than institutional or hospital settings. Cost differences between congregate and community settings depend on the context and country, but quality of life is better in the community.

IMPACTS OF COVID-19

Persons with disabilities and older persons are at greater risk of COVID-19 infection, and also at greater risk of adverse outcomes including death once infected. In countries with lower rates of COVID-19 infections at population level, care home resident deaths represented a lower proportion of all deaths. Publicly available data from 21 countries up to 26 January 2021 showed that an average of 41% of deaths linked to COVID-19 were among care home residents. Mortality in care settings was highly correlated with the total number of COVID-19 deaths in the population (Comas-Herrera et al 2021). In countries with lower rates of COVID-19 infections at population level, care home resident deaths represented a lower proportion of all deaths. In Belgium, France, the Netherlands, Slovenia, Spain, Sweden, the UK and the US, over 5% of care home residents died of COVID-19 (one out of every 20).

In high-income countries, most governments implemented guidelines to reduce infection and mitigate impacts of COVID-19 in congregate care settings, which covered the use of personal protective equipment (PPE), hygiene and testing protocols, cohorting and isolation strategies, as well as restrictions on visitors, external providers and social activities. However, those actions were often slow to happen.

The situation was more complex in low- and middle-income countries (LMICs), as many settings are basic and informal, and often not registered with government authorities. A common experience across much of the world was that care providers faced shortages of protective materials, difficulty in identifying access routes and responsibilities for procurement of equipment, and escalating prices. Governments prioritised the acute health sector.

Access to COVID-19 testing and delays in getting results have been major problems too, particularly in the early months of the pandemic. To limit the spread of COVID-19, the use of 'cohorting' has been reported, i.e. caring for infected individuals in separate parts of a facility and by different staff.

Some countries prohibited admission of new residents to care homes. While this measure protected vulnerable residents, it posed potential risks to the health and wellbeing of others in need of care, considering the lack of community-based services and adequate protocols for their provision. Also, in many countries, returns of residents to a care home after hospital treatment were banned unless these homes had the capacity to isolate returning residents.

Staff working in residential facilities have been identified as vectors of infection, especially if they worked in more than one facility. Some care staff moved temporarily into care homes to limit infection spread. In some countries, numbers of staff on sick leave led to a greater use of casual workers, creating problems in adherence to hygiene routines and potentially increasing infection risks. Care workers may have little employment protection in the event of illness, which may discourage them from stopping working even if unwell, thereby increasing risks to residents and other staff.

In several countries, residential care settings banned external health professionals, such as physiotherapists, speech therapists and other service providers, severely compromising the quality of care and worsening resident quality of life. Bans on visitors and the pausing of inspections to check care quality and adherence to care protocols raised further concerns.

Following bans on external service providers, some facilities introduced telehealth visits and virtual check-ins from therapists. Limitations on hospital treatment for care home residents led to some congregate settings operating effectively as 'COVID-19 hospitals' without

support from appropriately skilled healthcare professionals. Moreover, in some countries, persons with disabilities were initially prevented from transfer to hospital, although that restriction was later removed. Another common issue was lack of palliative care for older persons living in congregate care.

In some countries, shortages of medication for persons living in mental health hospitals have been reported as a consequence of COVID-19.

Strategies addressing infection prevention and management have already been taken in many countries, but those responses too often damage quality of care, reduce residents' quality of life and further undermine their human rights. Restrictions on visits and limited social interactions within settings have led to higher levels of loneliness, anxiety and depression, and distressing behaviours. These increased negative impacts led many care providers to introduce mitigating measures, such as enabling regular phone calls or virtual meetings between residents and their families, or 'window visits'. As the number of cases subsided following the first wave of infection, some countries started to re-enable social contact between residents and their families, but further waves have seen reversal of some of these practices.

In contrast to older persons being confined in their care homes, some national governments required children in residential care to be returned to their families. The usual support for this process could not be provided during the COVID-19 pandemic, leading to concerns about child safety and long-term family stability.

Expert committees, humanitarian and human rights organisations have started to reflect on the COVID-19 situation in congregate care settings in a number of countries and have highlighted several concerns. These included: social isolation causing unintended harm; the need for balanced person-centred approaches; and allowing access to health care services.

BARRIERS AND RESPONSES

A key barrier to deinstitutionalisation is prejudice against persons with disabilities and ageism, and therefore a lack of societal commitment to change the status quo. Stigma, poor understanding of disabilities and discrimination underpin many of the other barriers. Changing societal awareness and attitudes is imperative.

In some countries, institutionalisation is just beginning and is linked partly to the relatively recent growth in needs (for example, due to population ageing). In some low-income countries, a lot of congregate care is unregulated and unmonitored. Furthermore, even in countries with advanced deinstitutionalisation policies, there is a risk of 're-institutionalisation', for example in hospitals and community-based care homes.

Many persons with disabilities who live in community settings rely on family or friends for support. With suitable community-based services, families can ensure better quality of life than is experienced in institutional settings. However, there may be no family members or friends available to be carers – an increasing trend seen in many regions of the world. In addition, being a carer can lead to long-term economic disadvantages and other adverse consequences, mostly endured by women.

In many countries, a high proportion of public funding is allocated to the (relatively) small number of persons in institutions. This demonstrates the challenge of shifting resources tied up in institutions and making them available for community support.

The lack of legal and policy frameworks encompassing new community-based services in many countries creates a 'perverse incentive' in favour of placing persons with disabilities in institutions. In some insurance-based health systems, treatment and care have sometimes *only* been reimbursed in congregate settings, thereby encouraging providers to keep their institutions occupied.

Often large congregate care settings are major employers, sometimes in remote locations, and new employment opportunities may need to be created as part of a closure programme.

Institutions cannot be closed without ensuring that adequate community services are in place. Investment in community services needs to be generous enough and early enough in the process of changing the balance of provision to avoid adverse consequences such as homelessness or increasing use of restriction orders.

Alternatives to congregate care settings may be seen as 'too expensive' by decision-makers. However, the justification for deinstitutionalisation is to provide persons with disabilities and older persons with equal rights to live independently and be included in the community. In a *good* care system, the costs of supporting dependent individuals are usually high *wherever* those persons live, and policy-makers should not expect costs necessarily to be low in the community.

There are inter-individual differences linked to individual characteristics and circumstances, which deinstitutionalisation policies need to recognise and respond to, so as to optimise support and avoid exacerbating inequalities in access and outcome.

Institutions generally operate with a single budget, but good community-based care with a mix of services usually involves a number of different organisations and budgets. Co-ordinating across those budgets is imperative to avoid 'silo problems' of gaps and inconsistencies in support.

Double-running costs are needed during the development of community-based services and closing institutional care. It is often only when a large institution has *fully* closed that all of the budgetary savings are secured.

A linked barrier has been the way that international funding (from government and other donors, as well as international agencies) can be misallocated to institutional care instead of supporting initiatives that enable persons with disabilities to live and participate in the community. Institutional care may be easier to 'sell' to potential donors than dispersed family-based care.

Institutionalisation is defined by the *social* environment of a setting, and the opportunities available open to the persons living there, rather than its *physical* attributes. Furthermore, institutional culture can be replicated in community-based services, with limited choice and control and poor quality of support. It has been argued that deinstitutionalisation should also involve abolition of laws that allow 'substituted decision-making' that enable deprivation of liberty and coercive intervention.

Persons with disabilities and older persons should be supported to make informed choices about where they live, with whom they live, how they engage with services. The biggest barrier to deinstitutionalisation is that decision-makers do not listen to their views or respond to their preferences. The failure to recognise the needs of persons with disabilities, or their rights, leads to insufficient government budgets allocated to persons with disabilities.

In response to the barriers outlined here, some countries have introduced individualised funding systems such as self-directed support, which facilitate community living, expand choice and control, and offer greater flexibility with changing needs and circumstances.

The long-term timelines and the financial and other commitments necessary for successful deinstitutionalisation do not offer easy political gains, as the benefits of closing institutions and moving to community-based services may only be apparent some years later, and certainly beyond the usual electoral cycle.

Successful deinstitutionalisation requires long-term service planning, financial commitment and policy that looks beyond the electoral cycle. Deinstitutionalisation leads to better quality of life of persons with disabilities and older persons.

RECOMMENDATIONS

We recommend the following measures for governments, international bodies, service providers and civil society to shift the balance of support from institutional care to community-based services, and to improve the lives of persons with disabilities and older persons.

Improve societal awareness and tackle discrimination

- Address prejudice against persons with disabilities and ageism, including stigma and discrimination, through legislative and other channels.

- Commit to long-term action, given that, historically, societies have been resistant to change.

Involvement

- Involve persons with disabilities and older persons in all discussions of policy change and practice development.

Establish community-based care

- Develop high-quality community services to reduce the likelihood of institutions emerging and to ensure that closing an institution does not result in adverse consequences (such as homelessness, poor health or the use of restriction orders). Persons with disabilities living in community settings should enjoy a quality of life equivalent to that enjoyed by the rest of the population.

- Support persons with disabilities and older persons to make informed choices about where they live, and with whom. Support them to participate as fully as they wish in the everyday life of their community.

  Support persons with disabilities and older persons to make informed choices about how they engage with health, care and other services. Increase their control over decisions that affect their lives. Ensure flexibility in health, social care and other systems as individual needs, circumstances and preferences change.

- Ensure that institutional culture is not replicated in community-based services through, for example, restrictions on choice, independence and control. This must be the aim whether community services are provided by public, third sector or private sector organisations.

- Assist families to help them support the best quality of life for persons with disabilities. Reduce the immediate and longer-term adverse consequences of being a family carer.

- Ensure that every child, whatever their disabilities or needs, lives in a family setting.

- Ensure that older persons have the freedom to choose where they live (including through advance directives as necessary) and are not forced into a particular arrangement or place of living. Address human rights violations in any and every setting.

Commit adequate funding

- Recognise the rights and needs of persons with disabilities and older persons by committing sufficient funding to community-based support.

- Recognise that a high-quality community-based system of support for persons with disabilities and older persons may cost more than institutional care. Make a long-term commitment to protect the necessary additional resources.

- Transfer resources from institutions to community-based services. Plan for double running costs in the short-term until all resources currently tied up in institutions can be released. Ring-fence those transferred resources.

- Support countries to create systems that overcome the challenge of financing community-based services and supports from multiple budgets. Ensure that new inter-agency arrangements are cemented in place for the long-term.

- Create new employment opportunities for persons with disabilities as a key part of national strategies and local plans for closing institutions.

- Ensure that international funding supports initiatives that enable persons with disabilities to live and participate in the community, rather than reinforcing institutional structures.

Improve legal and policy frameworks

- Ensure that legal and policy frameworks incentivise community-based support and discourage the placement of persons with disabilities in institutions.

- Create incentives for health systems to finance and deliver high-quality care and support in the community rather than in institutions.

- Amend laws that allow 'substituted decision-making' that enable deprivation of liberty and coercive intervention.

Responding to pandemics and other emergencies

- Commit adequate resources to health and care systems to protect persons with disabilities and older persons, including conditions of employment for staff, training in infection control, and provision of PPE and other resources.

- Ensure lessons are learnt from evidence suggesting that infection prevention and control is particularly difficult in larger and more crowded congregate settings. Regulate so that new facilities are designed on non-traditional models and that existing settings are remodelled.

- Ensure that residents in congregate care settings and their families participate in decisions on measures that may constrain their freedoms over and above those restrictions considered necessary for the general population.

Commit to long-term action

- Recognise the need – through policy reform if necessary – for long-term financial commitment, service planning and monitoring to achieve successful deinstitutionalisation and better quality of life of persons with disabilities and older persons.

1 INTRODUCTION

The COVID-19 pandemic is highlighting the plight of large numbers of persons living in congregate care settings. Older persons in care homes across the world have experienced high risks of infection and mortality, with the number of COVID-19-related deaths of care home residents in some countries amounting to one out of every 20 residents (Comas-Herrera et al 2021). Younger persons with disabilities or long-term conditions living in congregate settings are also at above-average risk of serious health consequences or mortality. The pandemic is leaving many groups of people, including persons with disabilities of all ages, in heightened danger of infection, death, social isolation, neglect and abuse.

Congregate living settings have long been associated with a number of adverse consequences, not just during the COVID-19 pandemic. These include denial of autonomy, choice and other human rights; poor health and healthcare; low quality of life; social isolation; exclusion from society; physical, emotional and sexual abuse and neglect; and premature death. While congregate settings appear to offer opportunities to deliver specialist treatment or care, and to capture economies of scale when 24-hour care is needed, they have also sometimes been used as instruments of social and political control.

An institution is not a congregate living setting per se, but a description of how it operates and how it affects the lives of individuals who live there. An Ad Hoc Expert Group set up by the European Commission defined 'institutional culture' as follows:

> Any residential care where:
>
> • residents are isolated from the broader community and/or compelled to live together;

> • residents do not have sufficient control over their lives and over decisions which affect them;
>
> • the requirements of the organisation itself tend to take precedence over the residents' individualised needs.
>
> (European Commission 2009, p. 9)

The definition of independent living arrangements used by the Committee of the UN Convention on the Rights of Persons with Disabilities (CRPD) is as follows:

> Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment.
>
> (CRPD/C/GC/5 paragraph 16c 2017)

Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over

> their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living.
>
> (CRPD/C/GC/5 paragraph 16a 2017)

We use the term *deinstitutionalisation* in this report to refer to a process in which individuals move from, or do not move into, a setting that is institutional by the above definition to somewhere that is not isolated or isolating, where persons are not *compelled* to live together, where individuals have control over their lives and the decisions that affect them, and where the needs and rights of individuals are not subjugated beneath the requirements of organisations.

However, deinstitutionalisation is not simply the replacement of congregate with non-congregate living settings. Indeed, living in the community can, on some occasions and for some individuals, be experienced as 'institutional'. In practice, a policy of deinstitutionalisation will require development of a range of different services and arrangements in community settings, as well as efforts to prevent individuals developing needs for care and support (European Expert Group 2012).

We use the terms 'care' and 'support' interchangeably, given the extensive use of the term 'care', but we also recognise that many persons in the disability community prefer the term 'support' as a response to the idea of 'being cared for' and of the traditional role of cares (UN A/HRC/34/58 2016).

The aims of this report were: to summarise the evidence and experiences of persons living in congregate settings in general and in terms of the impact of COVID-19; to understand the barriers to deinstitutionalisation; and to highlight the approaches that have sought to overcome those barriers.

We were invited by the former United Nations Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, to conduct research to address the following four questions:

- What is the situation today in relation to institutionalisation of persons with disabilities and older persons?
- What has been the impact of COVID-19 on institutional care? How have governments responded?
- What are the arguments for deinstitutionalisation?
- What policy and other measures can be and are being taken to shift the balance of support from institutional care to community-based services?

We were asked to look at all constituencies among persons with disabilities and with long-term conditions that are or might be at risk of being subjected to institutionalisation, for all age groups, and at experiences across the world.

In the next section of our report, we describe the current situation in relation to congregate living for persons with disabilities, including children and older persons, and set out the associated challenges. This is obviously not, and cannot be, an encyclopaedic account of congregate living patterns across all of these population groups and across the whole world. What we have done is to identify some key statistics and experiences that highlight the main challenges associated with institutions, and to include some illustrative 'case examples' from a variety of settings and countries.

In Section 3, we describe the impact of COVID-19 on persons living in congregate settings, as well as some of the identified responses to the pandemic, again trying to offer evidence from around the globe. In Section 4, we reflect on the arguments for deinstitutionalisation, and the barriers that often appear to stand in the way. We consider how these may have altered as a result of COVID-19. We highlight examples of solutions and experiences to demonstrate how to overcome these barriers and to make progress towards better societal responses to the needs of different groups in the population, so as to ensure the best quality of life for individuals. We end with a series of recommendations for governments, international agencies, service providers and civil society.

2 LIVING IN CONGREGATE SETTINGS

In this section, we examine common themes pertinent to persons living in congregate care – children, persons with intellectual, physical and sensory disabilities, persons with psychosocial disabilities (sometimes called mental health issues or mental illness), and older persons – although there are, of course, numerous important differences between the experiences of these various groups.

Most of the available research evidence comes from high-income/Western countries, even though the majority of persons with disabilities live elsewhere in the world. In some countries, it can be difficult to identify congregate living provision because of an absence or lack of transparency of data about the living situation of persons with disabilities, or because of, as one author describes it, misappropriation of terminology (Crowther 2019). The situation is not helped by a lack

of monitoring or oversight of living arrangements worldwide (Delap 2011). Facilities are often unregulated and closed to outside scrutiny – especially some of those run by private agencies, faith-based or non-governmental organisations – and those that are situated in isolated localities (Browne 2017). However, the issues presented here are likely to be similar across a great many countries, even if their manifestations vary depending on local regulatory, economic, social and cultural contexts.

Another thing to mention at the outset is that it is not always easy to identify whether a particular setting is 'institutional' from available data: this depends in part on a country's legal framework and cultural interpretation, and especially on the degree of choice and autonomy that these contexts afford, encourage and support.

2.1 UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The UN Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, identifies the rights of persons with disabilities and the obligations of Member States to promote and protect all human rights and fundamental freedoms of all persons with disabilities. It also applies to persons with age-related needs.

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (CRPD, Article 1)

In Article 19, the CRPD sets out the right for persons with disabilities to live independently and be included in their communities and to choose where and with whom they live:

> States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

(CRPD, Article 19)

The CRPD Committee, the independent body in charge of monitoring the implementation of the CRPD, had issued a general comment on living independently and being included in the community, which develops standards for the implementation of Article 19 of the CRPD (CRPD General comment No 5 2017).

Regarding children, Article 23 on equal rights with respect to family life prescribes that, when the immediate family is unable to care for a child with disabilities, States must provide alternative care within the wider family and, failing that, within the community in a family setting (CRPD Article 23 (5)). The CRPD General Comment No. 5 (2017) stresses that 'large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. "Family-like" institutions are still institutions and are no substitute for care by a family' (p. 5).

Older age is associated with an increase in physical, mental and cognitive impairments. Although not all older persons have disabilities or impairments, many of the CRPD articles are relevant to all older persons; they also represent a significant proportion of persons living in congregate settings.

2.2 PERSONS LIVING IN CONGREGATE SETTINGS: NUMBERS AND TRENDS

CHILDREN

Millions of **children** around the world live in congregate settings. One estimate from 2006 put the total at 8 million worldwide (Pinheiro 2006); a more recent estimate suggests that between 5 million and 6 million children lived in institutions in 2015 (Desmond et al 2020). The actual figure is likely to be much higher, due to lack of data from many countries and the existence of many unregistered institutions (Csaky 2009; van IJzendoorn et al 2020). Regionally, estimated numbers of children living in institutions in 2015 were 1.13 million in South Asia, 1.01 million in Europe and Central Asia, 780,000 in East Asia and Pacific, 650,000 in Sub-Saharan Africa, 300,000 in the Middle East and North Africa, 230,000 in Latin America and the Caribbean, and 90,000 in North America (Desmond et al 2020). Each of these is a huge, unwanted total.

Studies of particular countries document and comment on trends in these numbers in more detail, such as for Central and Eastern Europe (CEE) and the former USSR (UNICEF 2018), Indonesia (DEPSOS 2007), China (Keju 2018), and Cambodia (Stark et al 2017). Even in the EU, where many countries have largely transitioned to family-based care, estimates of children still living in some form of residential care range from around 343,000 in 28 EU countries (Lerch and Severinnson 2019) to 1 million in 30 European countries (Eurochild 2020).

The rate of congregate living for children continues to rise in some countries, despite ongoing reforms and recognition of how it blights the lives of these children. For example, in Croatia, the number of children living in institutions increased by 3.7% in 2017 and the number of children

readmitted to institutions after having been in foster care also increased (Zrinščak 2019). In Lithuania, the number of foster carers diminished by 23% in the last decade (Poviliūnas and Sumskiene 2019).

A few other countries report reductions in numbers of congregate living settings, but careful interpretation may be needed. Between 2010 and 2015, Russia reorganised one in four of its child residential institutions by converting them into boarding schools, but the care in those settings is likely to have remained unchanged (Bobyleva 2015). Many unregistered institutions of low quality were closed in Ghana and Ethiopia (van IJzendoorn et al 2020).

Children enter congregate settings for various reasons, including poverty, disability, discrimination, ethnicity, disasters, parental death, parental ill-health, exploitation, neglect and cultural factors (children born outside of marriage to young mothers in some societies). In some countries, a disproportionate number of girls, children with disabilities and children from minority ethnic groups are placed in institutions (Csaky 2009). Contrary to common assumptions, over 80% of the children living in institutions have a living parent (Csaky 2009) and could potentially live with their families if they were given support.

Approximately 171,000 **children with disabilities** were living in residential care in the EU in the period 2010–16 (Lerch and Severinnson 2019); children with disabilities are significantly over-represented and constitute a large proportion of children in these kinds of settings (Mulheir 2012; Rau Barriga et al 2017).

- For example, of 95,582 children living in congregate settings in Germany in 2014, one in seven were children with disabilities (Hanesch 2019).

- In Romania, 30% of children living in institutions in 2017 had disabilities (Pop 2019).
- Institutional care for children with visual or hearing impairments often takes the form of boarding schools, for example in Austria, the Czech Republic, Germany and Italy (European Union Agency for Fundamental Rights [EU FRA] 2017a).

In CEE and Central Asia, children with disabilities are almost 17 times more likely to live in institutions than other children (UNICEF 2012).

In the US, around 29,000 children and adolescents with disabilities lived in congregate settings in 2009; a number that remains largely unchanged (Healthy People 2020). Around 6,000 children and young persons under the age of 21 with disabilities live in care homes for older persons in the US, due to insufficient state resources for community support and shortage of skilled home care workers. In many cases, the state only provides support for care home placements, leaving families feeling they have no other options.

Although Slovakia saw a 6% decline in the number of children in institutional care between 2013 and 2017, there was also a 10% increase in the number of children with disabilities, and no growth in foster family numbers. In Serbia, the capacity of residential institutions for children has been reduced; over 80% of the children there have disabilities (Crowther 2019). In Bulgaria, a reduction of 84% in the number of children in institutional care was reported between 2010 and 2016; however, there is evidence that many children and adults with disabilities were being resettled from larger to smaller institutions or 'group homes' (Rosenthal et al 2019; Case study A).

Group homes for children in Bulgaria

Following a documentary exposing appalling conditions in Bulgaria's orphanages in 2007, the state embarked on reforms to close its large institutions. The national strategy 'Vision for Deinstitutionalisation of Children in Bulgaria 2010–2025' set an objective of no children living in institutions by 2025. Since 2010, the EU has invested over €260 million in deinstitutionalisation in Bulgaria, with additional extensive support from private foundations and international charities (UNICEF 2017; Opening Doors 2017). As a result, all institutions for children with disabilities officially closed in 2015, and Bulgaria has been quoted as a success story and 'promising practice' for other countries to follow (UNICEF 2015).

Official reports suggest that the number of children in large-scale institutions had decreased from 6,730 in 2009 to 906 in 2017 (Structural Funds Watch report, 2018). Estimates suggest that in 2019, 3,325 children were living in group homes and around 1,000 children in large institutions, including babies and toddlers with disabilities (Academic Network of European Disability Experts [ANED] 2018–19). Some children have been transferred to group homes described as 'family-like' residential care. These are segregated facilities where young children, adolescents, and adults live together; about half are children with disabilities who usually remain segregated from society for life: 'There was EU money [for group homes]. That money needed to be spent. Getting that money meant profit…. It was not about the children. It was about the money. How fast you build and how much money you spent.' (Rosenthal et al 2019, p.13)

A recent report by Disability Rights International described findings from visits of 24 group homes, five day-care centres, four larger residential institutions, two schools, and other programs (Rosenthal et al 2019). It found 'dehumanising and dangerous conditions' in group homes and stressed that they were neither small nor were they family homes. Most had 14 beds, some congregated into 42 beds; some were located in the corridors of the old orphanages. Children with disabilities were reported to be living lives of isolation and neglect, in complete inactivity. They were left exposed to violence, abuse, and bullying, and denied medical care. Some children were kept in locked rooms or left alone in cribs permanently with no social contact. It was noted that staff frequently used restraints or high levels of medication as 'substitute for care'. Staff were not trained to help or engage the children in any way. Group home directors acting as legal guardians of large numbers of children created conflicts of interests. Even when children reached adulthood, they could not leave; in effect, they could not receive social support in another location: 'No one ever leaves. There are no new admissions until someone dies.' (p. 36). Also, the system incentivised keeping children in residential care: 'In June 2013, they decided to pay per day per child. So, if the group home is less than full, they get less money. This is when the incentive to fill the group homes started. A hysterical effort began to search for children to fill up each group home' (p. 14). The report concluded that internationally supported reforms replaced large, old orphanages with smaller but no safer new institutions.

Almost all the children in residential care have at least one living parent (Csaky 2009). It has been noted that many families in Bulgaria would keep their children with disabilities if they had support to help them, but as community support is very limited, the only options for them are group homes or international adoptions.

Every year, 3,800 children are separated from their families in Bulgaria; about a third are below the age of 3 years (ANED 2018–19). Many children remain at risk of being abandoned and placed in institutions rather than supported to remain in their families.

Recently, Bulgaria has announced plans to build many more new group homes, including for the youngest children, despite the calls of the UN Special Rapporteur on Health to stop building disability institutions and to adhere to commitment to deinstitutionalisation (Validity 2020).

<div align="right">Eva Cyhlarova, LSE</div>

ADULTS WITH DISABILITIES

Looking at all age groups, recent estimates suggest that there are still around 1.5 million **persons living in institutions** in 27 EU countries, including persons with disabilities (including psychosocial disabilities), those experiencing homelessness, children (including children with disabilities and unaccompanied or separated migrant children), and older adults (Šiška and Beadle-Brown 2020). These congregate living settings vary in size from 6 to over 100 places (e.g. psychiatric hospitals in Lithuania, care homes in Malta). With the exception of Sweden, all EU countries have some residential facilities with at least 30 places, and two-thirds of countries have some facilities with more than 100 places each (mostly psychiatric hospitals or residential care homes for persons with disabilities). Most institutions accommodate both persons with psychosocial disabilities and persons with intellectual disabilities, and often persons with different types of disability (physical, psychosocial, intellectual, sensory) live together, as in some German facilities. Persons with sensory impairments may be placed in specific institutions (e.g. in Austria, Cyprus and Bulgaria). Some institutions accommodate persons with severe disabilities, irrespective of type of disability, such as care homes in Belgium. In some countries, older persons with and without disabilities live together (e.g. in Cyprus or Bulgaria; EU FRA 2017a).

In the US, the number of persons with intellectual disabilities living in institutions continues to decline, and the number of small residential settings is growing; the total number of residential placements increased from 441,101 in 2010 to 680,851 in 2015. Between 2011 and 2013, the proportion of persons living in settings accommodating 1 to 6 persons increased from 77% to 80%, but the proportion living in settings accommodating 7 to 15 persons and group homes remained at 9%. Residential setting for 16 or more persons, including care homes, private and state-operated institutions, fell from 14% to 12% (Braddock et al 2015).

In Latin America and the Caribbean, only a small proportion of persons with disabilities are reported to live in congregate settings (care homes, hospitals, rehabilitation centres), but estimates may not include unregulated congregate settings. For example, around 5% persons with disabilities are accommodated in this way in Aruba and Guyana, and household surveys show similar patterns for Chile, Costa Rica and Mexico (La Comisión Económica para América Latina y el Caribe [CEPAL] 2012). Most persons with disabilities appear to receive support from their relatives, friends or neighbours, but need for care is growing in this region, just as it is in much of the world. A recent increase in private sector provision only benefits the few who can afford it, exacerbating social inequalities (CEPAL 2012).

Across Eastern Europe and Eurasia, **over 600,000 adults and children with disabilities** live in institutions, although data are unreliable. In 2010, of the 438,000 children living in residential care, 38% were children with disabilities (European Network on Independent Living [ENIL] 2013). Families often turn to institutions due to a lack of alternative care and the inaccessibility of many public services and facilities (Cravens et al 2019). In the Arab region, only Jordan has a clear deinstitutionalisation policy: a ten-year plan mandated by law to close institutions for persons with disabilities by 2027, to replace them with community-based facilities, and to provide training and financial support to families to help them accommodate persons with disabilities at home.

In South Africa, the number of beds in mental health hospitals – which are highly stigmatising and geographically inaccessible – decreased between 2000 and 2005 (Lund et al 2010), but this trend has not been maintained: for example, Free State province has seen a 4% increase. Two-thirds of discharged persons are readmitted shortly afterwards, due to the lack of community-based services (Docrat et al 2019). In Ghana, between 75% and 90% of persons with psychosocial disabilities discharged from hospital experience symptomatic relapse and are readmitted (Akpalu et al 2010).

Positive changes leading to more independence have been reported for adults with disabilities in some countries. For example, Šiška and Beadle-Brown (2020) report that some form of personal

assistance is available in 16 out of 27 EU countries, and a further six countries are piloting or planning personal assistance services for adults with disabilities. Of the 7.8 million persons with severe disabilities in Germany, 12% were getting some form of individual support in 2017 (Rosken 2019). In Sweden, personal assistance is the main model of community-based care and has been available by law since 1994 (Šiška and Beadle-Brown 2020).

The number of persons with disabilities placed in congregate settings appears to be rising in some EU countries (e.g. in France, Spain, Romania, Estonia) and in other parts of the world. For example, Kenya has seen an increase in institutionalisation: psychiatric hospitals provide the majority of care for persons with psychosocial disabilities (Kiima et al 2004). On the other hand, in Ghana, there has been a push for strengthening community-based services for many years, and since 1976 community psychiatric nurses have been trained and posted throughout the country (Ofori-Atta et al 2010).

Some countries that had previously seen quite a strong deinstitutionalisation push may now be seeing a reversal of previous trends. For example, in Italy, progress achieved between 2009 and 2012 was largely reversed by 2015 and has stagnated since, and re-institutionalisation has been reported as a consequence of austerity measures. In Greece, the number of persons with disabilities living in institutions decreased by only 2% since 2013 (EU FRA 2017a).

A recent report on 27 EU countries confirms that persons with intellectual disabilities and complex needs are most likely to live in institutional settings (Šiška and Beadle-Brown 2020). Although congregate settings with large numbers of residents are less often used for persons with physical or sensory disabilities (Lafuma 2006), congregate care remains a major form of provision in some EU countries (Šiška et al 2018).

OLDER PERSONS

Ageing is associated with increased prevalence of chronic diseases and physical and cognitive impairments, which may result in disabilities. More than 46% of older persons worldwide live with a disability, and older persons represent the majority of the overall population of persons with disabilities (WHO 2012). A systematic review showed that disability is an important predictor for admission of older persons to residential settings (Luppa et al 2010; Giebel et al 2020). However, older persons (especially those who acquire impairments when older) may not see themselves as having a disability, and are more likely to perceive the decline of their physical and cognitive functioning as a 'normal' part of ageing (UN A/74/186 2019). In addition, older persons' internalised age stereotypes contribute to self-ageism which can have a detrimental impact on survival. Older individuals with more positive self-perceptions of aging have been shown to live 7.5 years longer than those with less positive self-perceptions of aging (Levy et al 2002). This effect was greater than for some physiological measures (such as low blood pressure or cholesterol) or low body mass index and exercise, which increase the lifespan by one to four years.

Increasing life-expectancy of persons with some disabilities (such as persons with intellectual disabilities) over recent decades accounts for a significant proportion of the growing demand for residential services in some countries (Patja et al 2001; Braddock et al 2015). Need for additional support will grow with the ageing of national populations, especially given that ageing is associated with deteriorating health. An example can be given from England, where the number of older persons (aged 65 and over) is projected to increase by around 50% over a 20-year period, with two-thirds of these older persons projected to have two or more serious or long-term health problems (Kingston et al 2018a). Many of these older persons will have substantial care needs: the number needing 24-hour care is projected to increase by more than a third to over 1 million, doubling among the very old (85 years and older) by 2035 (Kingston et al 2018b).

The world's **ageing population** has become a challenge for health and social care provision in all high-income and many middle-income countries. It will soon become a challenge in low-income countries too. In 2015, 12.3% (901 million) of the global population were aged 60 years or over. By 2030, this proportion will have increased to 16.4% (1.4 billion persons), and by 2050 to 21.3% (2.1 billion persons; Office for National Statistics [ONS] 2018). Africa will see the fastest increase: from 5% in 2010 to 11% in 2050 (UN High Commissioner for Human Rights [HCHR] 2012).

Care for older persons varies hugely across the globe. There is growing demand for, and provision of, places in care homes in some countries, including in the EU (Šiška and Beadle-Brown 2020). In some countries where care has traditionally been provided by families, there has been quite rapid development of congregate settings for long-term care (e.g. in China, see Case study B). Poverty, lack of community-based support and limited family support are key reasons for congregate living. For example, in Ethiopia, although care homes provide basic care, they are generally perceived as an unhappy place to live; residents consider that it was misfortune that brought them there (Teka and Adamek 2014).

In some societies, relatively few older persons are placed in care homes, for example, due to the culture of looking after one's elders, feelings of shame for inability to do so, or financial reasons. However, changes in family structure, urbanisation, migration, demographic changes (smaller families) and female labour force participation rates make it increasingly difficult for families and communities to provide informal care to older persons. High care needs and age-related frailty, coupled with lack of support for families and neighbours to continue to provide support, can often result in care home admission.

CASE STUDY B

Growing institutional care for older persons in China

In China, it is estimated that the number of older persons aged 65 and over will double over the next two decades, while at the same time the number of working age adults will decrease by 9.1% (UN 2017). Traditionally, older persons relied on unpaid care provided by family. However, demographic and socioeconomic changes, coupled with a one-child family policy, led to some families no longer being able to provide care to older persons. To respond to the challenges, a three-tiered long-term care system has been highlighted in several high-profile national policies since the beginning of this century, emphasising 'home-based care as its foundation, supported by community-based services and institutional care' (Feng et al 2020, p. 1364). A 'booming sector' of formal long-term care services has emerged in recent years, both in public and private sectors (e.g. Zhu and Walker 2018).

The development of care home capacity has been encouraged by financial subsidies from central and local governments (dependent on occupied beds; Shum et al 2015). As a result, the number of care homes increased over fourfold (from 44,300 to 204,000) between 2012 and 2019 (Ministry of Civil Affairs 2013; 2020). By the end of 2019, there were 44 long-term care beds per 1000 persons aged 65 and over, which was slightly higher than that in the UK (42.8; Ministry of Civil Affairs 2013; 2020). However, in government-operated care homes, the average occupancy rate of care home beds has decreased from 80% in 2008 to 55% in 2014 due to a dramatic increase in the number of residential care beds (Feng et al 2020). For example, by the end of 2019, the overall occupancy rate of residential care in Beijing was 43% (Beijing Municipal Civil Affairs Bureau 2019). Private sector care homes have rates below 50% and even lower in rural areas, due to poor conditions, limited services, stigma, and affordability issues (Feng et al 2020).

Several governmental initiatives have promoted home and community-based care, usually in cities (Shi and Hu, 2019). In the last decade, the development of community care has been accelerated with various service models such as community service stations for older adults in Beijing (Wang 2018). By the end of 2019, there were 64,000 care facilities and 101,000 mutual help groups for older persons in the community level (Ministry of Civil Affairs 2020). However, comparing with the dramatically increasing supply in residential care, the availability of community care is still very low. Unlike the number of care home beds that can be set as tangible policy targets, community care facilities seem 'unseen' and grow slowly (Feng et al 2020).

In summary, China is in the process of institutionalisation with regards to actual policy implementation. Care homes are regarded as a solution to a collapsing family-centred supported system. Although the government appears to emphasize community care, much more resources are allocated to care homes, which incentivises residential care as a result (Feng et al 2020).

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2.3 HUMAN RIGHTS

Article 19 of the CRPD, which we quoted above, gives all persons the right to live independently and to be included in the community, to choose their place of residence and with whom they live, and to live in dignity. To date, only few countries incorporated the recognition of the right in national legislation (e.g., Peru, Marshall Islands, Fiji and Iceland).

Currently, there is no equivalent treaty on the rights of older persons, but many of the CRPD articles are relevant to all older persons. The UN Convention on the Rights of the Child (CRC; 1990) identifies four rights as guiding principles: the right to life, survival, and development; non-discrimination; the best interests of the child; and the right to participate. Research shows that rights of children living in institutions are violated on many levels, raising concerns about the human rights legislative framework. Article 20 of the CRC allows placement of children in 'suitable institutions' and Article 23 on disability does not mention a child's right to family life, but focuses on children's development of independence and their access to health, education and other services. Given that the concept of 'best interests of the child' is open to interpretation, this has allowed some countries to justify institutionalisation of children. However, there is consensus that removing children from their families due to poverty or social reasons represents a violation of their rights (Mulheir 2012). Although children in street situations and migrant children are not mentioned in the CRC, they experience violations of many of the CRC articles, as outlined in the CRC General Comment No. 21 (2017) on children in street situations and general comment Nos. 3 and 22 (2017) on migrants.

Article 23 of the CRC details States' obligations to ensure the fulfilment of all rights for **children with disabilities**, including the right to live in the community on an equal basis with others and to be raised in a family environment (Crowther 2019). They should enjoy a full and decent life with dignity, self-reliance and active participation in the community (CRC 1990). However, children with disabilities often experience discrimination, poverty, social isolation, lack of services and support, and hostile environments (UNICEF 2013). The CRPD further clarifies the rights children with disabilities, in particular in Article 7 (equal rights for children with disabilities), in Article 19 (equal right to live independently and be included in the community) and in Article 23 (equal rights with respect to family life). According to the latter, States must provide alternative care within the wider family or within the community in a family setting, as mentioned above (CRPD Article 23 (5)). Children have the right to grow up in a family, and institutions, regardless of size or quality, are not adequate substitutes for family environment (CRPD General Comment No. 5 2017).

Rights to liberty and freedom of movement are fundamental human rights. However, States can deprive persons of their liberty in circumstances expressed by law. Many forms of **deprivation of liberty based on disability** are common across the globe, and include restriction of legal capacity, involuntary hospitalisation and institutionalisation. Provision of support, care and treatment may only be available if the person is placed in an institution (Flynn et al 2019). In some countries, deprivation of liberty is widely accepted in congregate settings, despite being prohibited outside of these settings by legal frameworks. Deprivations of liberty, such as placement in segregated settings without consent, should be recognised as directly violating the CRPD (Rau Barriga et al 2017), but are sometimes seen as 'an unavoidable consequence in the attempt to care and protect persons with disabilities' (Flynn et al 2019, p. 88).

Persons with intellectual disabilities and psychosocial disabilities receive poor quality care and support in many countries and their fundamental human rights are often abused, including the right to freedom, education and employment, citizenship, and health care (Patel et al 2018; see Case study C on Brazil). Many persons with psychosocial disabilities are deprived of legal capacity, potentially leaving them unable to make decisions, especially in relation to involuntary treatment in psychiatric hospitals (EU FRA 2012). The rate of involuntary admission or hospitalisation of persons with psychosocial disabilities has increased in high-income countries, e.g. in Europe, Australia and New Zealand (Sheridan Rains et al 2019; Salize and Dressing 2004). In England, for example, the number of involuntary admissions increased by as much as 36% between 2007/08 and 2015/16 (NHS Digital 2017).

Furthermore, most mental health legislation unfairly discriminates against persons with psychosocial disabilities and does not meet the requirements of the CRPD (Szmukler et al 2014; Gooding 2017). For example, the Mental Health Act in England and Wales (1983, amended in 2007) allows involuntary treatment and violates several articles of the CRPD: Article 4 ('no discrimination of any kind on the basis of disability'); Article 12 (persons shall 'enjoy legal capacity on an equal basis with others in all aspects of life'); and Article 14 ('the existence of a disability shall in no case justify a deprivation of liberty').

Human rights violations for children and adults with disabilities and older persons have been reported across the world, being especially visible prevalent in psychiatric and other long-stay hospitals or care settings. Individuals admitted to such institutions in some countries (for example in parts of Eastern Europe) may have little chance of returning to the community. 'Caged beds', chemical restraints and solitary confinement are still used. Physical and sexual abuse continues, and other inhuman, cruel and degrading treatments are too often experienced. Many such institutions are very overcrowded.

CASE STUDY C

Care for persons with disabilities in Brazil

There are 12 million persons living with at least one type of disability in Brazil – nearly 7% of its entire population. Over 5,800 adults with physical or mental disabilities are currently institutionalised; there are no national data available on de-institutionalisation trends. In April 2020, the Ministry of Women, Family and Human Rights announced plans to map out and support the institutions that provide 'help' to persons living with disability (Brazilian Ministry of Health 2020).

Brazil still has a long way to ensure that the rights of persons with disabilities stated in national laws are fully realised, particularly among persons with severe and progressive disabilities. The National Policy for the Integration of People with Disabilities (1999) aimed to advance the inclusion of persons with disabilities in terms of social protection (benefits, social assistance, health, housing) and social involvement (education, work, culture). Another national law states that persons with disabilities should have access to living arrangements of adequate infrastructure with group or individual

support services that respect and/or increase their autonomy and promote independent living (Brazil National Congress 2015). However, a report from the Human Rights Watch (2018) revealed that persons with disabilities were often confined in inhumane conditions, isolated from society and deprived of care and of their rights. Thousands of children and adults with disabilities often had their day-to-day care wishes denied and their privacy and freedom violated through physical restraints, shared accommodation with dozens of other persons; staff used tranquilisers to 'calm down' residents. Staff were not adequately trained and there were no strategies in place to support deinstitutionalisation and social involvement, and to respect individual agency. Members of staff felt that most persons with disabilities were left in institutions 'to die'.

The Social Assistance Reference Centres (CRAS) and the Specialised Social Assistance Reference Centres (CREAS) are spread across the country and aim to provide and guarantee complete protection for adults with disabilities who are dependent or need support (e.g. with tasks, mobility, or special care; Mélega et al 2020). The Basic Home-Based Social Protection Service aims to prevent social isolation and avoid institutionalisation, and is offered in 30% of all CRAS nationally; 37% of these services are provided for persons with disabilities. The 'Recovery/Welcoming Units' (Unidades de Acolhimento) are social protection residencies that support residents to return to their families when possible, or refer them to substitute families, or help them achieve full independence/autonomy (Mélega et al 2020). If none of these options are available, persons continue to live at the Units indefinitely. There are currently 5,797 Units in Brazil, and of these, 311 are exclusive for adults with disabilities, located across 21 of the 26 states. Nearly 60% of persons with disabilities have lived in these Units for over six years; 27% have severe psychosocial disabilities (Mélega et al 2020).

There are also day centres for persons with disabilities with some degree of dependency, and their families; they provide care for persons with disabilities during the day, reducing family burden. Multidisciplinary teams of social workers, psychologists, occupational therapists and cares provide meals, hygiene, medication, workshops and group activities, such as arts and other activities that reduce isolation both for persons with disabilities and family carers. This service helps expand the capacity of family care, strengthens bonds, expands access to rights, avoids situations of abandonment, neglect, violence, and long-term institutionalisation. Day centres also help recovery in situations of previous violence, neglec, and abuse. There are 1,641 Day Centres in Brazil located in 18% of the Brazilian municipalities. There are 2,664 CREAS distributed in 43% of Brazilian municipalities; 66% of CREAS offer Special Social Protection services for persons with disabilities, older persons, and their families. Of the 1,751 CREAS that offer Special Social Protection services for persons with disabilities, older adults, and their families, 92% do so both in CREAS and in persons' own homes.

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Some **older persons** living in congregate settings may not be able to express their wishes about where they would like to live, and as a result, others make those decisions on their behalf; ideally, based on the best interpretation of their will and preferences (CRPD General Comment No. 1 2014). In many cases, there is no clear legal basis for detaining older persons in secure care settings; this deprivation of liberty is a significant human rights issue in many countries (Steele et al 2020).

Traditionally, human rights of *persons living with dementia*, especially in relation to their care, have not been recognised (Cahill 2018). Older persons with dementia are often seen as incapable of exercising choice and autonomy, and third parties have assumed legal power to make decisions in their 'best interests' (Steele et al 2020). Over the last decade, the CRPD has instigated increased human rights recognition of persons living with dementia supported by all parties involved in their care and advocacy. There are, however, several barriers to realising older persons' human rights, to which we return in Section 4. These include a focus on physical safety and economic incentives created by what has been called the 'marketisation' of care. These have led to a narrow interpretation of 'duty of care', without considering the negative impacts of confinement on physical, mental and personal state of persons with dementia. However, as Steele et al (2020) argue in relation to persons with dementia:

> Mental capacity can become a barrier to realisation of human rights and a basis on which to deny persons with dementia the opportunity to express their needs and preferences. … [The] identified barriers to human rights highlight significant social, cultural and economic dynamics that cast persons living with dementia as incapable, dangerous, and burdensome, and ultimately as less than full humans.
>
> (Steele et al 2020, p.14)

In some countries, independent advocacy services have been developed, offering support to persons who may need it to some degree to make certain decisions, to ensure that their rights are respected, and to facilitate access to information and services (e.g. UK, Australia).

The use of **guardianship** and other substituted decision-making laws is common across many countries. It is used when a person's legal capacity is removed or restricted, so that they are not recognised in law as being able to make decisions about their life, and a guardian is authorised to make all decisions on their behalf. The system of guardianship is perceived as a significant barrier for persons with disabilities to live in the community (Parker and Bulic 2016). In this context, it has been suggested that, in some countries, persons with disabilities may be seen as only representing the income the state pays for them to the agencies that 'supply' guardianship. For example, the annual fees for substitute decision-making (as part of the guardianship system) in France was 700 million Euros in 2015 (Court of Auditors 2016). In this case, the legal framework provides disincentives for deinstitutionalis-ation for agencies with vested interests in congregate living. In the US, it has been reported that financial interests can take precedence over the rights of persons with disabilities. For-profit institutions often act as guardians for their residents, making personal and medical decisions on behalf of persons who have been declared 'incapacitated' (Prisons Without Bars 2017): 'The life you live is what someone else lets you live. You become an "unperson".'

It has therefore been argued that guardianship is in conflict with the CRPD and that it should be replaced with systems that support persons with disabilities to exercise their legal capacity (Parker and Bulic 2016; CRPD General Comment on Article 12 2014).

2.4 AUTONOMY AND CHOICE

The CRPD Committee General Comment No. 5, para. 24, states that:

> To choose and decide upon how, where and with whom to live is the central idea of the right to live independently and be included in the community. Individual choice, therefore, is not limited to the place of residence but includes all aspects of a person's living arrangements: daily schedule and routine as well as way of life and lifestyle of a person, covering private and public spheres in a daily and long term dimension.
>
> (CRPD General comment on article 19 2017, p. 6)

All persons have fundamental legal capacity and their preferences should be central to decisions about their own welfare, even in situations when they need support for decision-making, instead of others making decisions on their behalf (Freeman et al 2015; Patel et al 2018). Supported decision-making includes providing information and support, as well as assisting a person to execute their preferences (Flynn et al 2019; Šiška and Beadle-Brown 2020). When persons are unable to express their wishes by any means, even after support is in place, the CRPD Committee has recommended to use the standard of 'best interpretation of will and preferences' instead of 'best interests' (CRPD General comment on Article 12 2014).

Four elements are needed for a person to be able to exercise choice and control about how they live their lives and (if needed) about the services that support them (Knapp 2007):

- meaningful **diversity** in what is on offer – a range of lifestyle options and services, affordable for the payer (which could be the state or individuals and families);

- accessible and understandable **information** about those options – awareness of and access to the information, and assistance to act on the information if needed;

- **empowerment** of individuals (or perhaps family or other carers) to make informed choices – for example, active participation in decisions about their own care; autonomy and self-determination; and

- giving individuals **control** (and support to exercise it, if needed) over the decisions that affect their lives.

As already noted, many persons with disabilities have little or no control over where and with whom they live. Several factors are at play: limited recognition of rights of persons with disabilities as citizens; limited involvement in decision-making; inconsistent provision of advocacy services; limited ranges of housing and support options; insufficient financial resources; and pervasively poor support for expressed preferences. It is widely argued that community-based settings offer more choice and facilitate empowerment when compared to institutions that segregate and isolate, but many community settings still do little to offer choice or facilitate control.

Efforts made over recent decades to extend choice and control include person-centred support, self-directed support (for example, through personal or individual budgets, or direct payments), opportunities to employ personal assistants, peer-support networks, self-advocacy, and advance care planning. We come back to some of these in Section 4. However, financial restrictions and strict eligibility criteria for community support can reduce independence and sometimes even force persons to return to institutions (EU FRA 2012). For example, it has been reported that more than half of persons with intellectual disabilities in Ireland had no choice about where and with whom they lived (Inclusive Research Network 2010), and almost half of persons with intellectual disabilities in the UK had no choice about where they lived and a third about *with whom* they lived (Hatton and Waters 2013). Arrangements can also be 'very complex to

access, only available to some persons, limited by a lack of available services to purchase and were sometimes seen by governments as a way to save money' (Šiška et al 2018, p. 107).

Persons with psychosocial disabilities may be excluded from community life by long involuntary placements in psychiatric hospitals, insufficient mental health support in the community, financial pressures, lack of reasonable adjustment at work, and stigmatisation and discrimination (EU FRA 2012). A review of the Mental Health Act in England and Wales, while not challenging involuntary hospitalisation, concluded that, even when persons are deprived of their liberty, they should have a greater say in decisions about their care and treatment (Wessely et al 2018). Advance directives and joint crisis plans, which determine and formalise a person's priorities and preferences about a potential future crisis, can reduce involuntary treatment and compulsory admission to psychiatric hospital (Thornicroft and Henderson 2016; de Jong et al 2016). Families may play a more important role in decision-making in some LMICs in comparison to more individualistic cultures common in high-income countries (Patel et al 2018), suggesting that there may be no universal agreement on the importance of the priorities and preferences of persons temporarily unable to make decisions.

However, there is a general consensus that coercive measures restrict human rights and that it is imperative to explore alternatives to coercion based on the rights, will and preferences of the individual (CRPD Article 12; Gooding et al 2018). A lot of attention has focused on *recovery*, not in the clinical sense of symptom alleviation or cure, but in a broader, personal sense:

Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

> Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. Recovery is often a complex, time-consuming process.
>
> (Anthony 1993, p. 527)

Patel et al (2018) describe this as the fourth in a series of 'transformational shifts that heralded the emergence of global mental health' (p. 1557). The first shift was the move away from purely biomedical interpretations of psychosocial disability, recognising 'the multi-faceted nature of the course and treatment' of such disabilities. The second was the progressive movement from institutional to community care, i.e. deinstitutionalisation. The third was to shift the focus away from a single group of experts (psychiatrists) to a diversity of specialist and non-specialist providers, both within and outside health care systems, and including peer-supports. The fourth shift was then the 'fundamental, rights-based' approach that emphasised recovery in this sense. Personal recovery is, however, embraced as an objective and set of policy principles in only a few countries. The challenges and opportunities associated with a human rights-based approach to mental health have been outlined in the UN Report of the Special Rapporteur on the role of the determinants of health in advancing the right to mental health (2019), which states that:

> Good mental health and wellbeing cannot be defined by the absence of a mental health condition, but must be defined instead by the social, psychosocial, political, economic and physical environment that enables individuals and populations to live a life of dignity, with full enjoyment of their rights and in the equitable pursuit of their potential.
>
> (UN A/HRC/41/34 2019)

In some countries, older persons living in care homes often have very few opportunities to make personal decisions or exercise choice or control over their lives, and many perceive their move to care homes as a loss of independence and autonomy. This situation has been particularly exacerbated during the COVID-19 pandemic, as we discuss in Section 3. Time spent in passive activities, doing nothing, sleeping and waiting, can lead to boredom, loneliness and depression (Brownie and Horstmanshof 2011). A study in Ireland found that residents of care homes reported their sense of independence being overwhelmed by the institutional system, lack of consideration of their needs, no opportunities to change the environment, developing a dependency syndrome and being given undesirable or cold food (Timonen and O'Dwyer 2009).

If an older person is thought or expected in future not to be able to make decisions for themselves (because of a neurodegenerative condition such as Alzheimer's or Parkinson's), advance care planning can support autonomy, accommodate preferences for future care and improve the quality of end-of-life care (e.g. Hall et al 2011). Advance statements can set out general preferences and document decisions to refuse specific medical treatment in specific circumstances. For persons with dementia, advance care planning can be conducted with a carer taking into account the person's apparent wishes and previously expressed preferences. Provision of advance decisions is currently available in the US, Canada, Australia, England and many European countries, within slightly different legal frameworks (Dixon et al 2018).

Children's choice and autonomy are much more dependent on the willingness of others to grant them these opportunities, which makes them particularly vulnerable. Children usually have no power to make decisions about their lives (Patel et al 2018). In this vein, the CRC Committee has stressed that assessment of a child's best interests must include respect for the child's right to express his or her views freely and due weight should be given to said views in all matters affecting the child (CRC, General comment No. 14 2013).

2.5 QUALITY OF CARE

Denial of rights and restrictions on autonomy and choice are inextricably linked with quality of care, although high quality care can still be provided in the context of other human rights violations (such as deprivation of liberty or legal capacity). And, of course, quality of care is a key driver of an individual's quality of life. (We will not get into deep discussion at this point as to what is meant by 'quality of life': it can have both objective and subjective meaning, it can be narrowly defined in terms of something akin to hedonic wellbeing, or more broadly defined in something similar to eudaimonic wellbeing.)

Quality of care for **children** in congregate living settings is often low, with inadequate food, hygiene and health care, and poorly trained and remunerated staff (Browne 2017). These factors contribute to the risk of neglect, abuse or exploitation of children in those settings (Boyce et al 2020; Browne 2017). Children may experience maltreatment from both peers and staff, including visitors and volunteers (see Case study D on India). Even when basic needs are met, institutions cannot provide sufficient social and cognitive input for children's adequate physical, cognitive or socioemotional development (van IJzendoorn et al 2020). There may be signs of progress in some countries, although modest in scale. For example, support for families and use of foster families has increased in the 12 countries supported by EU investment between 2014 and 2020 (Šiška and Beadle-Brown 2020).

Many countries rely heavily on congregate living for **persons with disabilities**. However, as there are no international quality standards for congregate living, care provided in these settings is often of poor quality, in addition to common breaches of fundamental human rights, such as deprivation of liberty. Residents are often segregated from society due to remote locations, abandonment by families and social stigma (Shen and Snowden 2014). Many congregate settings are in poor physical state and not equipped with basic amenities such as toilets, beds or personal space. Persons living in these settings often experience neglect and abuse, and many are forcefully detained, tortured or treated without consent (Human Rights Watch

2012). Shortages of staff and high staff-to-resident ratios lead to low quality care and lack of individual attention. Persons with disabilities experience many forms of discrimination, marginalisation, and lack of access to services and life opportunities (e.g. Drew et al 2011).

In Kenya, Mathari Hospital is the hub for psychiatric services of the country, with capacity of approximately 700, although the number of inpatients at any given time exceeds this (Anab et al 2018). Most residents have been brought by family members and, due to the stigma associated with psychosocial disabilities, many stay for longer than might be considered clinically necessary or get readmitted shortly after discharge. Ghana has a similar problem with overcrowding in its three government psychiatric hospitals, caused partly by stigma and partly by the free lodging and food provided, which is an attractive offer for families who are not able to provide care (Adu and Oudshroon 2020; Ofori-Atta et al 2010). Mean occupancy rate is 155%, making it unlikely that residents will receive adequate care, and putting staff at high risk of burnout (Akpalu et al 2010). The congestion of these institutions is exacerbated by lack of human resources and adequate community care to help reintegrate individuals after they leave hospital (Adu and Oudshroon 2020).

Despite research showing how to improve outcomes for persons with **psychosocial disabilities**, many individuals still spend their lives in closed psychiatric hospitals, subject to abuse, neglect and human rights violations. Institutionalised care limits resident autonomy and restricts their freedom; involuntary admission or treatment are common (Chow and Priebe 2013). Community care that promotes independent living and recovery is not available to most of the global population and care is often available only in institutions or prisons (Patel et al 2018). However, over the last half century, Western Europe, North America, Australia and New Zealand have seen a marked shift from institutional care to community-based models, leading to decreases in the number of psychiatric beds. The quality of community care varies considerably, depending on various factors including

financial resources and social acceptance,
but generally persons achieve better
outcomes living in the community.

CASE STUDY D

Institutionalisation of children and persons with disabilities in India

There are roughly 20,000 documented children with disabilities living in childcare institutions across India. Approximately 10,942 have learning disabilities and 9,040 have physical disabilities. There is a greater number of boys than girls. The highest number of children with disabilities in institutions was Karnataka with 4,236 children. Andhra Pradesh has 4,227, Kerala 1,922, Rajasthan 1,238, and Telangana 1,463 documented children with disabilities living in institutions (Ministry of Women and Child Development 2018).

There are many reasons why children end up in institutions, including poverty, social deprivation, illness or disability, humanitarian crises, child abuse and neglect, trafficking, and lack of accessible community services at home such as schooling or healthcare (Boyce et al 2020; Rau Barriga et al 2017). In India, many are orphaned or abandoned by their parents or found as runaway or missing children. Persons with psychosocial or intellectual disabilities found wandering on the streets are taken to institutions by the police if they are felt to be a danger to themselves or others, or if they are deemed to be incapable of looking after themselves. They may be unable to leave the institution and can be kept there for life (Sharma and Rau Barriga 2014). The alternative is often living on the street; there may be no other options.

Despite a distinct shift in national policies from institutionalised to community-based care (Ministry of Women and Child Development 2018), there does not appear to be a source of funding to provide the infrastructure to aid this transition. Nor has there been an appropriate societal shift, for example, with regards to the stigma faced by persons with disabilities.

Many institutions in India are unregistered. There has been official recognition of this fact following a Supreme Court directive to the central government of India to map or document all childcare institutions throughout the country. This is a challenging task due to the variety of establishments that exist. Approximately 91% are run by non-government organisations and 9% are government supported (Ministry of Women and Child Development 2018). Institutions can be overcrowded, dirty and lacking in adequate sanitation or hygienic practices, with poor nutrition and inadequate staffing (Sharma and Rau Barriga 2014). Lack of funding contributes to all these problems (Rau Barriga et al 2017).

A particular risk in all institutions is abuse of all kinds, including neglect, physical, emotional and sexual abuse. The long-term harm caused by abuse is well documented. Children can be mixed with others of different levels of vulnerability and risk, due to factors such as age, sex, and previous behavioural history or disabilities (Browne 2017). Children with disabilities are most at risk of abuse. In India and Indonesia, girls with disabilities have been found at an increased risk of violence, including sexual violence, in both government and privately-run psychiatric hospitals and institutions. Closed institutional settings act as barriers to reporting violence and abuse. In cases from India, persons with psychosocial or intellectual disabilities living in institutions were prevented from attempting to access adequate healthcare as a result of their disability or their inability to leave the premises (Sharma and Rau Barriga 2014).

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Quality of care services and supports for **older persons** in many congregate settings around the globe is poor. Older persons in some countries live in unhygienic, cramped conditions, often without access to electricity or water (Department of Social Development, South Africa 2010). Abuse of older persons in congregate settings is common; in a recent systematic review and meta-analysis of abuse in institutional settings, 64% of staff admitted to abuse of older persons in the past year (Yon et al 2019). Outdated ways of working may keep older persons alive by meeting their basic needs, but their dignity, functional ability and choice are often compromised. Even in well-funded care systems, residents' perspectives on quality of care are often overlooked, but the voice of the resident may be insufficient to bring about change (Sion et al 2020).

In South Africa, formal long-term care is available to a small number of persons who can afford to pay for private residential care (such as in retirement villages), or to the most destitute persons who are looked after by charitable bodies, but most older persons do not have access to organised services (Aboderin and Owii 2016). Publicly funded long-term care is subject to strict eligibility criteria. Most facilities have long waiting lists, despite reports of non-compliance with national norms and standards of service and racially discriminatory practices, both in admissions and quality of care (WHO 2017). There is an assumption that care for older persons is an individual's role or duty, linked to familial obligation and 'intergenerational solidarity'. However, many older persons report feeling trapped by the traditional organisation of family and care, with a desire to search for a life of their own (Freeman and Hoffman 2017).

In the Middle East and North Africa (MENA), care for older persons is primarily provided by families and communities. Population ageing is a relatively new phenomenon in the region, reflected in the lack of formal long-term care services. Rights to equality of older persons in most Arab countries are entrenched in their constitutions, so efforts have been made to provide services away from congregate living. The region is characterised by strong family connections and filial obligations, and where older persons and their families would prefer to continue living at home in old age. Recent research shows that resorting to care homes is regarded as an indication of almost 'being abandoned by the family' despite realising that care in a congregate setting might be necessary for older persons with specific needs (MENARAH Network). Several countries in the region have been reviewing their social development strategies to include elements specific to long-term care provision at home and in the community, with a clear emphasis on intergenerational solidarity. For example, in (high-income) Sultanate Oman, the Social Development Strategy (2016–2025) highlights the role of the family in providing or purchasing care services for older persons. Also, Turkey is in the process of developing person-centred residential care services for older persons (see Case study E). There is a more general question – across many regions of thew world – about filial piety laws or expectations which force or encourage older persons to rely on family members – usually adult children, especially daughters – for care and support. This disproportionately affects the lives of women and restricts choices for older persons (Chow 2006; Wu et al 2018; Woo 2020).

CASE STUDY E

Long-term care for older persons and persons with disabilities in Turkey

The National Plans for aged care and a National Dementia Care Plan in 2017 (Ministry of Family and Social Policy 2017) endorse a 'system of care' approach that is person-centred and enables independent living in the community for as long as possible. The plans recognised the need to develop well-organised and culturally sensitive residential care services with nursing for older persons with severe conditions and at advanced stages of dementia. Currently, there are a number of residential services provided both by the government and the private sector but vary considerably concerning quality and price.

To inform the development of these plans, extensive fieldwork and stakeholder interviews were conducted in 2016. The findings showed that the Ministry of Family and Social Policy has worked to meet some of the needs of different population subgroups, by providing cash benefits to older persons, pensioners and persons with disabilities, and also in-kind benefits such as retirement homes and admission to care homes. The Ministry has piloted new care ideas for older persons such as shared living and care centres. One of the innovative support mechanisms is peer-living. These 'houses' are organised by the state for a group of older persons to live together with the help of a support worker attending to their needs during the day. In 2017, there were 123 houses across Turkey. This model was developed to minimise isolation among older persons, and as an alternative to residential care settings which carries a certain level of stigma (Hussein 2017).

In 2017, there were 158 special care centres and houses for persons with disabilities (called umut evleri, literally meaning the 'houses of hope'), approved and regulated by the Ministry. There were also 99 organisations affiliated with the Ministry and providing regulated services to persons with disabilities in terms of care, rehabilitation and family consultancy centres.

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In many high-income countries, older persons living in care homes experience routines that aim to improve 'objective' quality of care but nevertheless offer very limited options for personalised support (Bradshaw et al 2012). In a systematic review of care home life, older persons reported a sense of institutionalised living, with regimented and restricted daily lives and limited stimulation. They were concerned about lack of autonomy and difficulty in forming relationships with others (Bradshaw et al 2012). In the UK, around 70% of persons in care homes have dementia, and many are perceived as 'vulnerable' and incapable of making decisions (Alzheimer's Society 2020), even though many persons with dementia can voice their concerns and preferences (e.g. Clare et al 2008). And a person-centred approach to support and activities in these settings can improve quality of life and health-related characteristics for residents (Ballard et al 2018).

Older persons, including persons with mild cognitive impairment, remain independent for longer if they can operate in their home environment, remain intellectually challenged (e.g. organise their own household), take part in daily activities (e.g. cooking) and exercise regularly (e.g. going on walks; Rossor and Knapp 2015; Livingston et al 2017). In contrast, Denmark implemented a policy of deinstitutionalisation during the 1970s, including a ban on building further 'traditional' congregate care settings and the encouragement of community-based arrangements. According to a WHO (2019) case report, over two-thirds of older persons with long-term care needs are now supported in their own homes.

The general picture, however, is that care workers in many countries are not provided with adequate training or employment conditions, and usually deal with high workload (Aboderin and Owii 2016; Olojede and Rispel 2015). In Slovenia, for example, residents perceived staff as exhausted or dissatisfied with their work; some thought that the poor attitude of staff led to lower quality of care; staff were meeting only physical rather than psychosocial needs of residents (Habjanič 2012). Residents often expressed desire for more communication with staff beyond mere greetings. A similar finding was reported in Ethiopia, where residents were living without basic amenities, but yearned for meaningful social interaction (Teka and Adamek 2014).

2.6 COMPARATIVE OUTCOMES AND COSTS

An indicator chosen to represent quality of care is only really relevant in so far as it is known to have an impact on the quality of life of persons receiving that care. Quality of life is often broadly defined to include (primarily) the subjective perception and experience of life of individual themselves, but also potentially the views of significant others, for example in situations where there are significant concerns about how to adequately support a person with high support needs and protect them from risks to their health or wellbeing. The effects that care services or support arrangements have on individuals are often called *outcomes* in health and social care contexts; they relate specifically to the extent to which an individual's needs are met and their preferences satisfied.

It will often also be important to take into account how a care or support system affect relevant other individuals in the lives of persons with disabilities, particularly close family members or others who provide support (usually unpaid).

OUTCOMES

Outcomes can span many dimensions. For example, the Adult Social Care Outcomes Toolkit (ASCOT), developed by researchers in England, working in close collaboration with older persons, distinguishes eight domains: personal cleanliness and comfort; food and drink; safety; clean and comfortable accommodation; social participation and involvement; control over daily living; occupation; and dignity (Netten et al 2012a). Note that 'control over daily living' was one of the domains that emerged out of the extensive consultation process, including with older persons with care needs. Different domain structures may be needed for different groups of persons, and of course each individual will have their own view as to the relative importance of those domains.

Strategic decision-makers – such as national, regional or local governments – as well as service providers and funders will generally be seeking to achieve the best possible outcomes from the resources they control. In the current context, they may therefore want to compare outcomes between congregate and non-congregate settings, as well as between whatever range of interventions might be considered feasible in terms of service types, individual therapies, staff deployments and so on.

Outcomes – using the term in this broad sense – are generally thought to be worse in institutional compared to non-institutional settings. Of course, some domains of outcome may actually be considered *better* in congregate settings than in non-congregate settings by or for some individuals. A psychiatric hospital provides shelter and food for someone who might otherwise be living on the street and hungry, but that individual may prefer the freedom of life outside the hospital setting, where they may have a social network which they prefer. Achieving balance is a challenge.

COSTS AND COST-EFFECTIVENESS

Strategic decision-makers, service providers and funders must also think carefully about how best to use their resources to achieve the target outcomes (EU FRA 2017b). For this reason, c*ost-effectiveness* is a relevant criterion for decision-making, ideally alongside other criteria such as protection of human rights, fairness, affordability and so on. In Section 4 we come back to the discussion of cost-effectiveness as a criterion to guide policy or practice – and we will note how its interpretation can raise issues – but for now we note that economic considerations should generally be taken into account.

Comparing outcomes and costs between congregate and non-congregate settings – or between any two or more treatment, care and support arrangements – is not always easy. Many comparisons have been made previously, some based on collection of sound evidence and its interpretation, and some not. Unfortunately, therefore, some of the arguments propounded in relation to deinstitutionalisation have the potential to be misleading.

For a start, the range of outcomes and costs to be included should be identical between the settings being compared. Congregate settings tend to provide a wide range of services for persons with disabilities living there, funding most of them from a single budget. In contrast, community services tend to be more fragmented (although not necessarily un-coordinated), with cost impacts often spread across a number of *separate* budgets, each managed by a different organisation or part of government. Those various budget impacts, wherever they may fall, should *all* be included in any comparison with congregate settings. In addition, there are often costs associated with the time inputs of family carers, perhaps linked to constraints on taking up paid employment or other opportunity costs of their time. The general point is that comparisons of relative outcomes and costs between congregate and non-congregate care should be careful to be equivalently inclusive.

A second limitation quite commonly found in previous studies and commentaries is a failure to recognise what can be quite marked differences between the characteristics of persons living in congregate settings and those living in non-congregate settings, in particular in respect of characteristics which have cost implications. For example, if someone needs help with the activities of daily living,

this will increase staff or family carer time in supporting them, thereby increasing cost. Comparing costs or outcomes between settings without taking account of differences of this kind would be erroneous and potentially misleading. In other words, comparing the costs of supporting, say, older persons living in a nursing home with the costs of supporting older persons living independently in the community, and then arguing that nursing homes are expensive, would *only* be valid if those two groups of older persons had identical strengths and needs, or – if their strengths and needs differ, which is likely to be the case – if the data are adjusted statistically to correct for such differences.

A third consideration is that costs and outcomes vary between individuals, potentially quite markedly, because individuals themselves vary in their circumstances, aspirations, strengths, needs and preferences. Those differences ought to be taken into account in making comparisons, and especially because policy and practice recommendations are often based on what happens *on average*, and so might overlook diversity. Outcomes may be very good for some individuals and very poor for others; costs may be high for some groups and much lower than average for others. An appropriate societal response to strengths, needs or preferences would therefore not be identical across all persons.

AVAILABLE EVIDENCE

We cannot attempt here a comprehensive account of comparative outcomes or costs between different types of setting or different interventions for persons with disabilities and older persons. Anyway, as just noted, there will be potentially marked differences in outcomes and costs between individuals, with some of those differences perhaps associated with observable characteristics such as age, gender, ethnicity or cultural preferences, and certainly with strengths, needs and preferences. There will also certainly be differences between countries, partly because of the aforementioned considerations, but especially because of variety in available treatment, care and support options, which could then generate differences in relative costs.

We highlight some general findings here, and discuss the implications in Section 4.

Children

There is abundant evidence showing the negative impacts of institutionalisation on children's health, development and life chances (e.g. Berens and Nelson 2015). For example, in Russia, adults who spent their childhood in institutions had severely reduced life chances and life expectancy; many had criminal records (20%), ended up in prostitution (14%) or died by suicide (10%; Pashkina 2001). It has been known for several decades that children growing up in institutions have difficulties forming healthy emotional attachments (Bowlby 1951). In addition, children under the age of three are at risk of permanent

developmental damage when placed in institutions rather than in family-based care (Csaky 2009). A recent meta-analysis confirmed that institutional care was associated with substantial developmental delays and deviations, including delays in physical growth, brain development, cognition, attentional competence and effects on physical health and socioemotional development (van IJzendoorn et al 2020).

The longer children spent in institutions, the worse were the outcomes. The 'English and Romanian Adoptees' study demonstrated the link between duration of deprivation and degree of post-institutional recovery (Sonuga-Barke et al 2017). Children who lived in institutional care for long periods showed significantly higher prevalence of attention-deficit hyperactivity disorder and disinhibited social engagement symptoms even after 20 years in adoptive homes. Children who had experienced institutional care for shorter periods were mostly indistinguishable from what were described as the non-deprived adoptive group. This difference between children exposed to long or short durations of institutional care was already established by age 6 years.

Despite these negative impacts, congregate living is still the first choice of alternative care in many countries for children whose biological parents are unable to look after them. The availability of institutions presents families with the possibility of placing children in institutional care, and governments have not committed sufficient resources to develop family-based options. Instead, large proportions of public funding are spent on institutions instead of supporting children and families to live well in their communities (Csaky 2009; EU FRA 2017b). We return to this and related points in Section 4, but also note here that institutional care may be easier to 'sell' to potential donors than dispersed foster family care.

There are obviously overwhelmingly strong moral arguments, based on child welfare and future life chances, for replacing all congregate care settings with family-based support, whether with biological, adoptive or foster parents. In these circumstances, evidence on cost-effectiveness is largely irrelevant, but evidence on relative costs is not. This is because decision-makers may

take the view that the funding needed to support families could come from savings generated by closing institutions. Would those savings be sufficient? Numerous studies suggest that they would be, finding wide cost differences between congregate and family-based care: see, for example, Desmond and Gow (2001), Carter (2005), Mulheir (2015), National Audit Office (2014) for evidence from a diverse range of countries. But some of the other available research fails to address the complications of comparison that we emphasised above, thereby exaggerating potential cost savings and in turn risking the under-funding of community-based arrangements (Knapp and Fenyo 1989).

> Institutionalisation of children is not a necessity – it is a choice. There are cost-effective alternatives that allow children to live in a protective family environment.
>
> (Lumos 2017)

Creating an effective system of support for family and community-based care requires initial investment, of course, but these costs can be offset against the longer-term savings, because more children will develop into healthier, happier adults who are less dependent on state services compared with adults who grow up in institutions (Csaky 2009). Similarly, early intervention of various kinds can improve the chances that children with disabilities can complete education and enter employment later on, which could again reduce longer-term public expenditure on support services (Mulheir 2012; Walsh et al 2003). A challenge to which we return later is that resources need to be committed perhaps many years before those economic pay-offs are achieved.

Persons with psychosocial disabilities

Research comparing community-based services with congregate living for persons with psychosocial disabilities has consistently shown better outcomes in terms of self-reported quality of life, housing stability, clinical symptoms, engagement with services, and vocational rehabilitation. There are a few key 'inflection points' which determine subsequent outcomes and costs.

Timely support for persons with psychosocial disabilities is a key inflection point (Clark et al 2018). Early intervention for young persons experiencing psychosis has been shown to be effective in allowing those individuals to remain living in the community, attending school and pursuing employment careers (McDaid et al 2016). Responding quickly and appropriately at a point of 'crisis' (another inflection point) can improve some clinical outcomes, reduce impacts on families, and improve both the individual's and the carer's satisfaction (Murphy et al 2012), whilst also generating significant reductions in service costs (McCrone et al 2009). Then there is a plethora of community-based arrangements designed to support individuals in their own homes and communities; for some arrangements there is good evidence of both short- and long-term benefits to individuals and of efficient use of scarce societal resources, although local context has a bearing on findings (Catty et al 2002; Patel et al 2018). Supporting homeless persons with psychosocial disabilities has become a major challenge in many countries, but there are approaches which can both enhance quality of life and avoid hospital admission (Aubry et al 2015).

Particular attention has focused on the closure of long-stay psychiatric and similar institutions, giving residents the opportunity to return to community living. As Patel et al (2018) state:

> The evidence from deinstitutionalisation in high-income countries is unequivocal – when hospital closure programmes have been done reasonably well, and not used as a reason to reduce the overall mental health budget, the overall quality of life, satisfaction, and met needs of people with long-term mental disorders who move from hospital to community care is improved. In terms of the overall global picture regarding deinstitutionalisation, community-based models of care are not inherently more costly than institutions, once the needs of individuals and the quality of care are taken into account. (p. 1584)

Key components found from reviews of the evidence are the careful planning of closure programmes, early investment in appropriate community services and ongoing support, ideally framed by strong commitment to principles of recovery. However, costs increase with level of need, so community-based care will probably not be resource-saving for individuals who need the most support. Better outcomes for persons with psychosocial disabilities generally follow from more generously resourced community support arrangements (Knapp et al 2011).

The most intensive and long-running evaluation of hospital closure, conducted in England by the Team for the Assessment of Psychiatric Services, followed up over 700 persons for 12 years after they moved from two large hospitals in London to community settings (after they had been resident in hospital for an average of 17 years). Five years after leaving hospital, 90% were still living in the community, very few were homeless or in contact with the criminal justice system, and about a third had been admitted to hospital at least once (Trieman et al 1999; Leff 1997). Another long-term English study that followed persons after they had left hospital (after, on average, 23 years of residence) similarly found broadly good outcomes, although social inclusion and participation in the community were modest (Beecham et al 2004). Across many studies it has been found that the majority of persons strongly prefer living in community rather than institutional or hospital settings (Taylor et al 2009). Much can be done to support individual recovery ambitions (Bredewold et al 2018), and in ways that are clearly affordable (Knapp et al 2014).

Persons with Intellectual disabilities

Research on the impact of deinstitutionalisation on persons with intellectual (or learning) disabilities shows that a move from institutions to community living is associated with improved quality of life (McCarron et al 2019). Participants in the various studies included in this comprehensive, careful review – all conducted in high-income settings – reported improved sense of wellbeing, freedom, and independent decision-making. Other researchers have pointed to positive changes in adaptive skills such as self-care, independent functioning, self-direction and

social skills; and in quality of care, including some degree of self-management and autonomy and respect for human rights (Bredewold et al 2018; Larson et al 2012).

However, results on integration into the community are mixed – exactly as was found for persons with psychosocial disabilities – highlighting the importance of services and family support to facilitate engagement and inclusion. Some negative effects have also been reported, such as undetected physical illnesses, redistribution of care (improved care for some groups leading to care deterioration for others), criminal behaviour and victimisation of persons with disabilities (Bredewold et al 2018).

A systematic review of the cost implications of deinstitutionalisation for persons with intellectual disabilities – following individuals as they moved from long-stay residence in hospital to new community-based settings – found only two studies meeting eligibility criteria for inclusion in the review. One followed a group of individuals who were living in 'long-stay hospitals' in England (with length of stay ranging from 4 to 69 years, around a mean of 27 years), and who then moved out to a variety of community settings. Some of these individuals were followed up for another 12 years: costs were higher in the community but quality of life was better (Hallam et al 2006). The other study found costs to be lower in the community for a group of persons with intellectual disabilities leaving long-stay hospitals in Northern Ireland (but did not report statistical significance) and quality of life to be much better (Donnelly et al 1994).

Many variants of community-based residential setting have been developed for persons with intellectual disabilities, such as village communities, residential campuses, staffed and unstaffed group living, dispersed housing schemes, 'shared lives' arrangements and fully independent housing. Costs and outcomes vary between them, although not all studies have adequately addressed the issues we raised earlier in relation to consistent breadth of cost measurement and recognition of differences in relevant characteristics of persons between types of setting.

Higher costs are associated with settings which accommodate persons with higher levels of intellectual disabilities and distressing behaviours, with smaller residential settings likely to be more expensive (Hallam et al 2002). Another study compared residential campuses and dispersed housing schemes (accommodating between one and eight persons per house), finding better quality of care and quality of life in the dispersed housing schemes, but also higher costs (Emerson et al 2000). Felce et al (2008) compared semi-independent living, which allows individuals with intermediate support needs to receive staff support for specific purposes, with fully staffed group homes: persons in the former type of setting had better outcomes for choice and community activities undertaken without staff support, but poorer outcomes in relation to money management and some health indicators. Semi-independent living had lower costs and offered certain lifestyle advantages.

Older persons

Older persons living in congregate care face multiple negative experiences, including feelings of loneliness, sadness, anxiety, worry about illness, insecurity and lack of comfort (Gardiner et al 2020; Ibrahim 2009). Loss of autonomy affects residents' functional skills, which can lead to decline in their quality of life (Teka and Adamek 2014). A recent systematic review and meta-analysis found a negative association between congregate living and quality of life for older persons (de Medeiros et al 2020). Lower quality of life and lower levels of happiness have been reported by older persons living in care homes compared to their counterparts living in the community (Gardiner et al 2020). In India, residents of 'old age homes' reported poor physical health (Dubey et al 2011), and there are similar studies from a number of other countries.

Care homes may be considered inherently social living arrangements and some strive to provide person-centred care; however, rates of loneliness reported by care home residents have been reported to be significantly higher than for persons living in the community (Gardiner et al 2020). Superficial relationships with staff and

other residents, limited contact with family, feelings of 'not belonging' and few opportunities to form friendships all contribute to loss of social connectedness (Buckley and Carthy 2009). Social isolation has a negative impact on older persons' mental and emotional wellbeing (Smith and Rosen 2009). For example, social contacts have been associated with better mental wellbeing in residential care in South Africa (Chipps and Jarvis 2016). Severe restrictions during the COVID-19 pandemic on visitors into these congregate settings and on visits out by residents may have severely exacerbated these negative experiences, as we discuss in the next section.

Cost comparisons between congregate and other settings face the same challenges as those already mentioned for persons with disabilities and for children. As a general rule, the cost difference between, say, nursing homes and community settings will be wider when the overall proportion of older persons in the population living in those congregate settings is smaller. This is because nursing homes usually accommodate persons with the greatest needs, including many who have dementia. It is perfectly acceptable to compare the average costs of these two broad types of setting, but it is unacceptable to then infer that congregate settings are in some sense 'too expensive' unless careful account is taken of differences in the typical level and complexity of health and care needs of the different groups of older persons, and of course, of the outcomes that are experienced by older persons themselves. Similarly, it is quite reasonable to calculate what percentage of total public or societal expenditure on older persons is allocated to nursing homes or other congregate settings – a recent calculation for England was that residential and nursing care accounted for 64% of spending on long-term care for older persons in 2017/18 (NHS Digital 2018) – but wrong to jump from this to the conclusion that this is necessarily wrong on either efficiency or equity grounds. Again, we come back to these arguments in Section 4.

3   IMPACTS OF COVID-19

The COVID-19 pandemic and the actions taken by governments in response to it have had devastating impacts on health, life-expectancy, social and economic activity, and quality of life. The UN Office of the High Commissioner for Human Rights Guidance on COVID-19 and Persons with Disabilities (2020) has highlighted the attitudinal, environmental and institutional barriers that persons with disabilities face, and that have been reproduced in the COVID-19 response. Persons with disabilities and older persons are at greater risk of infection and also at greater risk of adverse outcomes once infected, whether living in congregate settings or elsewhere. Individuals living in congregate care settings have been disproportionately affected, resulting in high rates of infection and death. These experiences highlight the challenges faced by persons with disabilities and older persons, and at the same time crystalise many of the arguments about deinstitutionalisation. The World Health Organisation published a Policy Brief in July 2020 (WHO 2020), in recognition of the need for concerted action to mitigate the impact of the COVID-19 pandemic across all aspects of long-term care.

In this section we draw on information from a number of sources, particularly from the LTCcovid initiative (www.LTCcovid.org) and the Corona-older platform (www.corona-older.com). Both of these web-based sources are continuing to gather evidence from across the world, and to arrange online events to discuss a wide range of issues linked to COVID-19; here we are only able to include material up to mid-March 2021. Much of the evidence summarised here relates to older persons, and particularly those living in congregate care settings, many of whom live with dementia and/or other conditions that generate complex care needs. There is much less evidence to date on the impact of COVID-19 on other groups, such as children or adults with disabilities.

3.1 HIGH INFECTION AND MORTALITY RATES

The LTCcovid initiative has been gathering international data on numbers of COVID-19-related deaths among care home residents. (Terminology for the congregate living settings varies between countries; here we use the term 'care homes' unless a specific piece of evidence requires some other term.) Publicly available national data up to 26 January 2021, covering 22 countries, showed that an average of 41% of deaths linked to COVID-19 were among residents in care homes. Mortality in care settings was highly correlated with the total number of COVID-19 deaths in the population (Comas-Herrera et al 2021). In countries with lower rates of COVID-19 infections at population level, care home resident deaths represented a lower proportion of all deaths. In Belgium, France, the Netherlands, Slovenia, Spain, Sweden, the UK and the US, over 5% of care home residents died of COVID-19 (one out of every 20). (In this, as with other cross-country comparisons, country differences in definitions and data may complicate interpretation.) The relationship between prevalence of COVID-19 in the community and deaths in care homes has also been observed in studies looking at variations *within* countries (Stall et al 2020; Barnett et al 2020). Recent migration patterns have also exacerbated COVID-19-related issues for some persons with disabilities in previously 'safer' rural regions, as in Romania (Safta-Zecheria 2020).

There is very limited information available on infection and mortality rates of younger persons with disabilities and persons in different care settings. A study from England found that patients aged 65 and older in psychiatric inpatient settings (56% of patients had been diagnosed with dementia) had, in comparison with those living in the community, a higher risk of getting infected with COVID-19. There was also a greater proportion of deaths from COVID-19 among inpatients (Livingston et al 2020b).

Data from England and Wales reveal a significantly higher rate of COVID-19-related deaths among persons who were reported to have disabilities in the 2011 Census than among those who did not (ONS 2020). Furthermore, a report on persons with learning disabilities in England found that 54% of deaths among those in residential care were related to COVID-19. This was only slightly higher than among persons with learning disabilities receiving support in the community (53%). Information from Public Health England suggests that care settings for persons with learning disabilities were less likely to experience COVID-19 outbreaks than other care homes (such as those for older persons). This may be due to lower numbers of beds in each setting (Public Health England 2020).

Data from the US also suggest that persons with intellectual and developmental disability (IDD) are at greater risk of death due to COVID-19. Turk and colleagues (2020) describe how individuals with IDD are at greater risk of poor COVID-19-related outcomes among younger persons. This may be due to higher prevalence of relevant comorbidities among persons with IDD. Relatedly, an article in the *New York Times* reported that by 6 April 2020, the COVID-19 death rate among persons with IDD in receipt of services within the state of New York was 9.5%. This stands in sharp

contrast to the overall death rate of 4.0% at that time (Hakim 2020; Sabatello et al 2020). By November 2020, a report from the US showed that persons with developmental disorders and persons with IDD had comparatively high odds of dying due to COVID-19 (Makary 2020).

A press release from researchers at the Catholic University of Applied Science in Germany further points to Dutch and Swedish research. Data on 1000 persons with intellectual disabilities in the Netherlands (90% living in residential care settings) indicate a death date of 13% by the end of May 2020. This is comparable to the death rate among the general population. The Swedish data, on the other hand, report a lower death rate (7.7%) among persons with intellectual disabilities living in state-provided residencies. At the time of those calculations (11 May 2020) the COVID-19 related death rate among the general population was 12.7% (Dieckmann et al 2020). Another report from Baden-Württemberg, Germany, showed that more persons with intellectual disabilities got infected with COVID-19 (0.10%) compared to the general population (0.02%); however, case fatality did not differ (5.49% vs.5.94%). Almost all individuals with intellectual disabilities who contracted (98.9%) and all of those who died (100%) of COVID-19 lived in residential care settings. The analysis also showed that persons with intellectual disabilities were less frequently hospitalised than all other COVID-19 patients (19.2% vs 7.69%), but also died more frequently when hospitalised than patients of the general population (71.43% vs. 31.39%). This information is based on data up to 10 June 2020. The report, however, was based on voluntary responses from health authorities, and only 26.3% of health authorities responded and not all responses were complete (Habermann-Horstmeier 2020).

3.2 IMPLEMENTATION OF MEASURES TO KEEP RESIDENTS SAFE

In high-income countries, most governments issued (and have updated) guidelines to reduce infection and mitigate impacts of COVID-19 in long-term care settings, after several countries experienced high number of deaths among older persons living in care homes. These guidelines covered use of Personal Protective Equipment (PPE), hygiene and testing protocols, cohorting and isolation strategies, as well as restrictions on visitors, external providers and social activities within care settings. A challenge is that many congregate care settings are run by non-public providers (for-profit or non-profit – often religious organisations), and although usually registered with relevant authorities, implementing a coordinated and effective response to the pandemic took time.

The lack of administrative oversight has become a substantial problem during the COVID-19 pandemic, with little known about infection rates, capacity issues (loss of revenue) and available support, thereby creating barriers to the 'design and implementation of policies' (Browne et al 2020; López Ortega and Sosa-Tinoco 2020).

In response to limited government oversight, independent groups and care providers in some countries developed preventive guidelines and measures, sometimes followed later by government action, such as in Brazil, India, Mexico and Jamaica (Da Mata and Oliveira 2020; Rajagopalan et al 2020; López Ortega and Sosa-Tinoco 2020; Amour et al 2020). In Thailand, several private care facilities translated and distributed international guidelines, such as material provided by the WHO (Sasat et al 2020). However, while detailed guidance and advice from governments, independent organisations and international bodies such as the WHO will be technically very good, many of the recommendations may be impossible to implement in care settings with limited financial resources and lack of necessary infrastructure (Lloyd-Sherlock et al 2020). These latter authors recommend establishment of a task force to identify 'the simplest and most affordable measures' for implementation in resource-poor settings.

CASE STUDY F

Long-term care facilities in South Africa responding to the COVID-19 pandemic

The STRiDE (Strengthening responses to dementia in developing countries) project team in South Africa collected information on the situation and experience of residential care homes for older persons with the help of a questionnaire between 14 May and 5 June 2020 and between 15 June and 2 September 2020. The team received feedback from for-profit and not-for-profit organisations from all nine provinces in South Africa. At least two of the care homes 'served obviously underprivileged communities'. COVID-19 infections, recoveries and/or deaths among residents and/or staff were recorded in 16 of the 47 care homes.

The survey found that care homes found it challenging to constantly keep up with updated policies and procedures, which as some respondents pointed out had been inadequate, 'last minute' and vague, leaving care homes to develop their own policies based on available information. Where clear guidelines and training were provided, these were welcomed. Care homes also experienced additional financial challenges as they incurred additional expenses from purchasing PPE and other hygiene products, but also faced additional cost for accommodating, feeding and looking after staff that in some cases temporarily had moved into the care facilities. The inability of taking in new residents as well as lack of payments from families of residents who had become unable to pay the monthly fees and hygiene products for their relatives added further to the financial strain. Financial relief and in-kind support varied greatly between provincial government departments.

Care home providers felt that while government departments placed demands on the sector, there was little support provided in return. In the first survey some care homes reported that they were unable to purchase PPE, one home reported to be 'in dire need of food' and another, providing care for underserved communities, described a shortage of water from the local municipality, which led to reliance on borehole water. In the second survey responses showed that the situation worsened, 'with retrenchment and the sale of units being reported'.The care homes worked hard to educate staff and resident on the necessary hygiene measures without spreading fear and noted increased workloads due to the implementation and adherence of protocols. The survey further addressed issues around space, planning for isolation units and concerns around the impact on residents with dementia in care homes if isolation strategies need to be put in place. Delays in receiving results of COVID-19 tests also posed challenges to providers. Some reported having to adapt to new means of communication (e.g. video calls). Care homes highlighted the impact the situation had on the emotional wellbeing of staff and residents. Sometimes preventive measures, such as mask wearing and physical distancing, had to be weighed up against the negative impact they had on residents' wellbeing, particularly of persons with dementia.

Care homes reported challenges around the implementation of no visitor policies and the impact these had on residents and staff. Most care homes developed visiting policies to enable visits for relatives nearing the end of life. In addition to the workload around hygiene and physical distancing measures, care homes also needed to think of ways to occupy residents and to respond to residents' frustration that usual group activities, church services and hairdresser visits had been cancelled. Some care homes developed exercise programmes, provided emotional supports to residents, and celebrated special occasions to counteract this impact. One care home, for example, invited prepared special meals and invited residents and sponsors to send presents to 'make Mother's Day special'. Some providers also developed special measures to respond to the needs of persons with dementia. Respondents stressed the great effort that staff undertook to keep residents and each other safe and well (Ashwell et al 2020).

This case study is based on Jacobs et al (2010) and LTCCovid Country Reports
and summarised by Klara Lorenz-Dant, LSE

AVAILABILITY OF PERSONAL PROTECTIVE EQUIPMENT (PPE)

While many governments, professional associations and care providers were relatively quick to develop hygiene protocols and update guidelines on use of PPE, care providers in many countries faced shortages of protective material, difficulty in identifying access routes and responsibilities for procurement of equipment, and escalating prices.

This appears to have been the case in many high-income countries during the first waves of the pandemic. Shortages of PPE in Italy, coupled with the priority given to the acute health sector, left nursing homes struggling, although there were also examples of good practice in some regions (Berloto et al 2020). Lack of PPE in Spanish care homes made it hard for staff to follow hygiene protocols. Two-thirds of 179 assisted living facilities in the US surveyed in March 2020 were unable to access enough PPE (Van Houtven et al 2020). A similar survey in the Netherlands found

almost half of care home staff 'experienced pressure to work without having adequate PPE' (Kruse et al 2020). Care workers in Thailand had only very limited access to PPE, creating increasingly stressful situations for residents and staff (Sasat et al 2020). In Sweden, volunteers helped to address initial PPE scarcity by producing plastic aprons and shields for care workers supporting older persons (Szebehely 2020).

Protocols for use of PPE have evolved as understanding of COVID-19 transmission mechanisms has grown. For example, early protocols in Spain only required use of PPE with symptomatic residents (Zalakaín and Davey 2020), and in Sweden, decisions on the use of face masks for care were initially made locally and only in June 2020 did the Public Health Agency provide general guidance (Szebehely 2020).

A common additional challenge for the social care sector was the priority for

allocation of PPE initially given to acute health sector (e.g. in Denmark; Rostgaard 2020). Some government bodies later became involved in acquisition and distribution of supplies when spiking prices on the open market made it hard for care providers to acquire supplies. In Germany, the National Association of Statutory Health Insurance Funds committed to supporting care providers with PPE costs, and federal states have started to support care providers in PPE acquisition (Lorenz-Dant 2020). The Agency for Integrated Care in Singapore began supporting nursing homes with supplies from the national stockpile in early February (Graham and Wong 2020), and the Social Care Standards Authority in Malta enabled PPE bulk buying in late March 2020, following concerns that care providers would struggle to afford it on

the open market (Fenech et al 2020).

But this is not the case around the world, and many care homes continue to have difficulties accessing sufficient PPE, in part because the cost is considered unaffordable by providers or residents' family members who cannot afford to pay for equipment, in addition to the considerable burden of care home costs. In Malaysia, some care homes have received (uncoordinated) donations of PPE through social media campaigns and other means (Hasmuk et al 2020). In Mexico, guidelines reflected the limited availability of PPE by stating that only one member of staff should look after residents suspected of COVID-19 and that this person must wear PPE (López Ortega and Sosa-Tinoco 2020).

ACCESS TO TESTING

Access to testing for the virus and long delays in getting results have been a major problem, particularly early in the pandemic. Over time, testing has become more widely available for individuals living and working in residential care settings, such as in Sweden, Austria, Denmark, Finland and Germany (Szebehely 2020; Schmidt et al

2020; Rostgaard 2020; Forma et al 2020; Lorenz-Dant 2020). But even when testing regimes have improved, wide variations in access often remain, such as in England (Rajan et al 2020), the Netherlands (Kruse et al 2020) and in Minnesota (US; Arling and Arling 2020).

CASE STUDY G

Asymptomatic persons with COVID-19 in care homes in Malaysia

In Malaysia, as highlighted above, the number of unregistered care facilities is high. In addition to the 15 residential care homes and 2 homes for terminally ill persons run by the government and the 320 private care home registered with the relevant health authorities and despite efforts by the Ministry of Health through additional legislation to register all private care home, there over 1,000 residential care facilities that remain unregistered.I

n the face of the COVID-19 pandemic and the impact it had on care homes around the world, the Director General of Health pursued an unconventional approach by announcing in early May 2020 a mass-testing strategy in an effort to keep its 'most vulnerable population' safe. This mass-testing strategy of certain groups did not just include all registered but also all unregistered care homes. The results from this comprehensive approach, undertaken in May, which tested staff and residents of 267 facilities identified 0.2% of COVID-19 cases among this population. Of those who tested positive 85.7% were asymptomatic (Hasmuk et al 2020).

The case study is based on Hasmuk et al (2020) and summarised by Klara Lorenz-Dant, LSE

COHORTING STRATEGIES

Over time, there has been growing use of a process sometimes referred to as 'cohorting' to try to slow down and interrupt the spread of COVID-19. 'Cohorting' is when those individuals who may be infected and those unlikely to be infected are cared for in separate parts of a care facility and by different groups of staff. In Turkey, for example, nursing home residents were moved into single rooms (where possible) and staff members assigned to particular floors in an effort to reduce transmission (Akkan and Canbazer 2020). Guidance in Germany advises care homes to move residents and their contacts into single rooms, preferably with their own wet room, and to create cohorting zones (including dedicated space and staff; Lorenz-Dant 2020). Nursing homes in Singapore and New Zealand introduced split zones to enable residents and staff to move freely within each of the self-contained 'bubbles' (Graham and Wong 2020; Ma'u et al 2020).

However, the structure of the built environment can create considerable barriers to infection prevention and management in care facilities, particularly in low-resource settings where single rooms are unavailable. Evidence from the US suggests that non-traditional small house nursing homes (such as the Green House model) have had fewer COVID-19 cases and deaths (Zimmerman et al 2021). In Ontario, Canada, it was found that COVID-19 outbreaks were associated with older design standards (shared bedrooms and washing facilities; Stall et al 2020). In England, 60% of care home managers reported in a survey that they had not always been able to isolate residents with suspected COVID-19 (Rajan et al 2020). In countries such as Brazil, Malaysia and China, where individual rooms are less commonly available, guidelines recommend transferring infected residents to dedicated hospitals or other medical facilities ('sanitary houses' in Chile) to achieve physical separation (Da Mata and Oliveira 2020; Hasmuk et al 2020; Shi et al 2020; Browne et al 2020; Sani et al 2020).

RESTRICTIONS ON VISITORS

In most countries, congregate group settings initially responded to the pandemic by closing their premises to visitors, in some cases ahead of (or against) government guidance. In many countries, exceptions were made for residents nearing end of life, or for other special reasons. In Malaysia, exceptions included residents living with dementia and those exhibiting severe behavioural challenges if the routine of family visits got disrupted (Hasmuk et al 2020). In England, visits in care homes were banned, apart from in exceptional circumstances such as welfare or end of life. However, a few exceptional care homes continued to facilitate visits almost throughout the pandemic, working within the government guidance and following health and safety protocols. The care home managers thought that visitors were 'essential family carers' who were 'integral to residents' lives' (Sky TV News 2021). They felt that 'to refuse to [allow visits] would be to discriminate against people in their final days', as many residents with dementia might not recognise their relatives in a matter of months (BBC 2021). Unfortunately, many care homes continue to ban visits (apart end-of-life visits), despite government guidance that visiting policy should be based on a dynamic risk assessment and the needs of residents should be taking into consideration (DHSC 2021). An international review of visiting at care homes during the pandemic highlighted the negative impact of visiting restrictions on the wellbeing and mental health of residents, their family members and staff and recommended that blanket visiting bans should not be used (Low et al 2021).

RESTRICTIONS ON SOCIAL INTERACTION WITHIN THE CARE SETTING

In addition to visitor restrictions, congregate care settings have been advised to reduce the social interaction of residents *within* the settings. In China, all gathering activities were suspended and in Hong Kong SAR it was recommended that residents stay in their own rooms and avoid activities and social interaction with others. Meals were

also encouraged to take place in individuals' rooms (Lum et al 2020; Shi et al 2020). Similar measures were introduced in Finland, with more in-room dining (Forma et al 2020). In Denmark, on the other hand, daily activities did not get completely cancelled. Instead, managers were encouraged to plan gatherings in smaller groups, ideally with no more than two residents at a time. It was also recommended that staff members should engage only with a specific group of residents to reduce risk of cross-infection if there was a COVID-19 outbreak (Rostgaard 2020).

The likely negative impact of prolonged social isolation on these groups was also recognised in Germany, where advice from the Robert Koch-Institute for older persons and persons with special needs living in residential care settings (as of May 2020) outlined that small groups of designated residents should be enabled to participate in collective activities, thereby enabling individuals to maintain social interaction but limiting the number of contacts (Lorenz-Dant 2020). In the Netherlands, nursing home residents are represented by client councils that have the right to participate in organisational decisions regarding the daily lives of residents. However, during the pandemic, nursing homes did not consistently include client councils in crisis management (Kruse et al 2020).

MEASURES TO REDUCE THE RISK OF STAFF BRINGING IN INFECTIONS

Staff working in residential facilities have been identified as vectors of infection (National Collaborating Centre for Methods and Tools [NCCMT] 2020), especially if they worked in more than one facility. In Canada, Israel and England, care workers were restricted to just one setting (e.g. Tsadok-Rosenbluth et al 2020). In Canada, however, this not only led to lower staffing levels (and potentially lower quality of care), but also care staff were allowed to keep jobs in other settings, including home care, working in assisted living group homes or performing cleaning services (Duan et al 2020), which would limit the effectiveness of a single site order (Hsu et al 2020).

Another mitigation measure in a few cases was for care staff to move temporarily into care homes. For example, in one residential care facility in Jordan that accommodates about 160 young men with a range of disabilities, the staff were split into three separate teams, each committing to living and working in the facility for a full week, followed by two weeks' leave. Similar arrangements have also been reported in some other facilities for persons with disabilities, for older persons, and in juvenile detention centres (Black 2020). In Malaysia, many care workers followed their employers' request to spend some time living in the care home, although compliance with these requests may have been helped by concerns regarding their employment if the care home became affected, as well as by difficulties in getting to their place of work because residential care settings for older persons were initially not considered essential services under the Movement Control Order (Hasmuk et al 2020). In Turkey, care staff worked 14-day shifts, living in the care settings and being tested for COVID-19 at the beginning of each working period (Akkan and Canbazer 2020). Some nursing home staff in Singapore were given alternative accommodation if their usual places of residence were identified as COVID risks: they were paid an additional allowance, provided with meals and specially arranged transportation by the government, and given access to professional counselling and other emotional support services (Graham and Wong 2020). A survey in France found that nursing homes where staff voluntarily moved into the care homes showed better outcomes in terms of infection rates and mortality (Belmin et al 2020).

In other countries, such as India, care providers reduced the number of staff on duty at any one point to reduce the number of persons entering care settings (Rajagopalan et al 2020), probably damaging the quality of care. Research from the US points to the importance of adequate staffing: 'poorly resourced [nursing homes] with nurse staffing shortages may be more susceptible to the spread of COVID-19' (Figueroa et al 2020).

MEASURES TO REDUCE THE RISK OF RESIDENTS BRINGING IN THE INFECTION

Some countries introduced policies that prohibited or discouraged admission of new residents to care homes for older persons (e.g. Malaysia, India, Jamaica, Malta; Hasmuk et al 2020; Rajagopalan et al 2020; Amour et al 2020; Fenech et al 2020). While these policies help to protect vulnerable residents, they pose risks to the health and wellbeing of others considered to need care and support. In Austria, this issue was addressed by creating bed capacity in temporarily closed rehabilitation centres (Schmidt et al 2020). In Turkey, public guesthouses and designated hotels were used for new residents, with means-tests to determine co-payments abandoned to allow free care access for all (Akkan and Canbazer 2020).

A second issue concerns the return of residents back to a care home after hospital treatment. In many countries, discharges from hospitals were banned unless care homes had capacity to isolate returning residents (e.g. Lorenz-Dant 2020; Fenech et al 2020; Ma'u et al 2020) and/or required tests for COVID-19 prior to the return (e.g. Hasmuk et al 2020; Graham and Wong 2020). In Turkey, residents could either return to their families for an isolation period or to special social isolation units (Akkan and Canbazer 2020). In some countries, however, protocol violations have been reported: in Malaysia, for example, there have been reports 'of doctors coercing reluctant care home operators to accept discharges without testing' (Hasmuk et al 2020), and some care providers in the US were pressured to accept returning residents who still tested positive for COVID-19 (Van Houtven et al 2020).

CASE STUDY H

Care homes in China during COVID-19 outbreak

In Mainland China, care homes were recognised as the high-risk areas at the very beginning of the outbreak of COVID-19 pandemic. Following the lessons learned during the SARS epidemic in 2003, the Guidance for Prevention and Control of COVID-19 in Care Homes was immediately issued by national ministries and commissions and updated in early February 2020. Local governments also deployed a string of measures to protect vulnerable groups. Care homes adopted a nearly closed-off management to prevent the potential risk of the virus spread.

Before the pandemic was under control in Mainland China, the following key measures were implemented in care homes: Face-to-face visits by persons from outside the care homes were prohibited;

• A 14-day self-quarantine was required for all residents, care workers and other staff before they checked in or retuned to care homes;

• All gathering activities within care homes were suspended;

• An emergency medical service plan for care home residents was launched locally to provide prompt medical care;

• A temporary isolation room was prepared for persons with fever or any other symptoms (Shi et al 2020).

Although some measures brought inconvenience and physically isolated the care home residents and staff at that moment, they were quickly understood by all, given the consensus on prioritising 'being safe'. Apart from some cases within care homes in Hubei province in the early stages of COVID-19 pandemic (Lu et al 2020), no more clustered COVID-19 infections were reported in residential care settings. For example, nearly 700 care homes in Beijing maintain zero COVID-19 infection (Xinhua Headlines 2020). However, some frail persons living in the community faced some living difficulties during the lockdown period when all community-based care facilities were suspended. Recently, some local governments suggested to extend eligibility for public-funded residential care for home-dwelling persons living alone, in poverty or with severe care needs. Not only the satisfying performance of care homes in coping with the spread of COVID-19, but also the low bed-occupancy rate of residential care suggest that there is sufficient capacity for receiving those new clients (Feng et al 2020; Shi and Hu 2020).

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ACCESS TO VACCINATION

With the approval of first vaccines from December 2020, many countries that have access to vaccines have prioritised care home residents and staff. Israel, Denmark, Scotland, Cyprus, some regions in Spain, Canada's provinces, England and Northern Ireland have completed at least the first round of this process, while other countries are close to achieving this goal (BBC 2021; Irish Times 2021; Lauter at al 2021). The provision of vaccination to care homes was complicated by logistical challenges around ensuring the cooling chain required for some of the vaccines as well as the delay in vaccine delivery experienced by countries. Other challenges in the long-term care sector include vaccination reluctance among some residents and staff, and consent policies for residents who lack capacity. Individuals with learning disabilities were only recognised in the priority list of few countries (e.g., Germany, UK; Lauter et al 2021).

CASE STUDY I

Vaccination in care homes in Canada

Already in November 2020, Canada's National Advisory Committee on Immunization set out that care home residents and staff should be among those first receiving the vaccine. Jurisdictional authority in health matters enabled provinces to add their additional priorities. These included that residents and staff should be vaccinated by February 2021. In addition, the provinces of British Columbia, Nova Scotia, Prince Edward Island (PEI) and Ontario included family carers of persons in residential care settings among the priority groups.

Different rollout policies may have affected the speed at which this goal was achieved. Furthermore, policies differentiating between public and private care homes have meant that in the province of Alberta all residents in publicly funded care homes have received the vaccine, while those in private 'undesignated' homes were not included. It was argued that the death toll in public homes had been 'heavier' compared to privately funded homes.

The focus on vaccinating persons living in residential care settings is likely to save lives. A modelling study provided by the Ontario Government's Science Table found that achieving the goal of vaccinating all LTC residents by 31 January 2021, rather than 15 February 2021, would likely prevent 'at least 600 new COVID-19 infections and 115 deaths by 31 March 2021'.

The case study is based on Sinha et al (2021) and summarised by Klara Lorenz-Dant, LSE

3.3 IMPACTS ON QUALITY OF LIFE

There is growing evidence of the negative impacts of measures adopted in congregate settings to reduce the risk of infections. There have been enormous restrictions on individuals' rights, such as the right to self-determination, the right to health, the right to live in the community, the right to private and family life, the right to informed consent and more (Dichter et al 2020; HRW 2020). Even before the pandemic, loneliness was common for persons in nursing homes (Gardiner et al 2020), with well-known negative effects on physical and mental health, especially of older persons (Courtin and Knapp 2017). The COVID-19 pandemic is likely to have exacerbated the situation (Schmidt et al 2020; Forma et al 2020).

In addition to the social interaction that visitors provide, many family carers also continue to play active roles in provision of

care and support for their relatives (Forma et al 2020). A review identified four ways of continued support by family members: 'hands-on' assistance at meal times or with personal care tasks; managerial and overseeing roles (e.g. accompanying residents to outside appointments, providing supplies and laundry, taking care of financial affairs); socioemotional support (information on social circles, engaging in activities); and hands-on assistance with refreshments, meals, leisure activities and social visits to other residents (Puurveen et al 2018).

Restrictions on visitors and visits have severely affected the wellbeing of care home residents who experience higher levels of loneliness, anxiety and depression, and aggravating mood and behaviour, with persons *without* cognitive impairment apparently most affected (Mo and Shi 2020; van der Roest et al 2020). Care home staff report uncertainty, hopelessness, work overload, and role-conflicts (Mo and Shi 2020). In the Netherlands, the number of aggression-related incidents reported among persons with intellectual disabilities in residential settings increased significantly following introduction of COVID-19 restrictions (Schuengel et al 2020). However, a report from the nursing home sector in Denmark suggested that, for the majority of residents, quality of life had increased due to less demanding activity schedules (Rostgaard 2020).

INTERVENTIONS TO MITIGATE THE IMPACT OF INFECTION PREVENTION MEASURES

Recognition of the negative impacts of lockdown on residents led many care providers and non-governmental organisations to introduce mitigating measures such as enabling regular phone calls or virtual meetings between residents and their families, or 'window visits'. In Kenya, for example, guidelines encourage staff to facilitate regular telephone or virtual conversations between residents and their social networks, and to promote resident wellbeing through affection communication and daily routines (Musyimi et al 2020). Similar efforts are also being made in Australia; although it has been pointed out that slow adoption of technology in what in Australia are called 'aged care facilities' and potential shortages in broadband and tools (such as tablets, smart phones) to access software may pose barriers (Low 2020).

As the number of cases subsided following the first wave of infection, some countries started to look for measures to re-enable social contact between residents and their families (Verbeek et al 2020). In Canada, policy recommendations for visitors have been developed after a review of international care home visitor policies (Stall et al 2020). In Minnesota, window and open-window visits (with both parties wearing masks), followed by supervised outdoor visits, were enabled in June 2020 (Arling and Arling 2020). In Denmark, criticism around restrictive measures and the impact on residents' mental health led to the explicit encouragement of outdoor visits (Rostgaard 2020). Numerous other countries (e.g. Malta, Italy, Austria, Canada, Germany, Singapore) have re-enabled in-person visits under strict protocols regarding, for example, visiting time, number of visitors and PPE requirements (Berloto et al 2020; Schmidt et al 2020; Hsu et al 2020; Lorenz-Dant 2020; Graham and Wong 2020; Fenech et al 2020; Low et al 2021).

Special holidays can be particularly challenging for persons living in care homes and their families. In Malta, care homes tried to soften the impact of Mother's Day without in-person visits by enabling relatives to bring personal gifts that were handed to residents following a stabilisation period (Fenech et al 2020). In Jordan, the government put in place guidelines to manage the safe collection, stay and return of residents who would like to spend the Eid Al Fitr holiday period with their families. Guidelines also considered safeguarding the health of residents who remained in the care facility (Black 2020).

3.4 IMPACTS ON QUALITY OF CARE

In several countries (e.g. Germany, Hong Kong) residential care settings closed their doors to external health professionals, such as physiotherapists or speech therapists, and other service providers, such as hairdressers (Dichter et al 2020). In Hong Kong, some occupational therapy services for persons with dementia were delivered with the help of IT (Lum et al 2020). In Jordan, only health visits by GPs and senior officials and inspectors from the Ministry of Social Development were permitted (Black 2020).

Bans on external care providers of these kinds damage the quality of care for persons living in congregate settings, and almost certainly damage the quality of their lives. Moreover, the inability of relatives to visit and the pausing of unannounced inspection visits to check care quality and adherence to care protocols raised concerns (e.g. in Australia; Low 2020). Visits to monitor care homes were also reduced in Malta, but care providers need to regularly supply information to the relevant authority over the phone, and when relatives of residents express concerns to the authority, these are followed-up through calls and visits (Fenech et al 2020). The inability of the relevant commission to visit care homes in Austria led to a parliamentary inquiry to establish how human rights of residents can be ensured during a pandemic (Schmidt et al 2020). In Sweden, an inspection of affected care homes and care units for older persons and persons with disabilities was conducted in mid-April 2020 to better understand the 'consequences of COVID-19 for quality and safety in care services'. It found divergence with regards to hygiene procedures in 10% of the 1000 care units investigated. Care settings that were not adhering to the required hygiene routines received follow-up inspections (Szebehely 2020). In Jordan, in contrast, Ministry of Social Development officials continued to visit, inspect and monitor residential care settings to ensure safe practices (Black 2020).

In Sweden, a high number of staff on sick leave has led to an easing of requirements and greater use of casual workers, in turn creating problems in adherence to hygiene routines. In response, a national e-training programme was developed to educate workers on hygiene practices. It was further found that homes with more casual workers had more residents with recorded infections. Some municipalities opted to offer casual workers more stable contracts to enhance their ability to self-isolate when necessary without incurring economic consequences (Szebehely 2020). In many countries, care work is a precarious occupation, and workers may have little employment protection in the event of illness, which may then discourage them from stopping working even if they feel unwell. This poses considerable risks to residents and staff (e.g. López Ortega and Sosa-Tinoco 2020). Better employment conditions and hiring campaigns (e.g. in Israel; Tsadok-Rosenbluth et al 2020) may have helped with securing staffing (see also Pierce et al 2020; Hsu et al 2020). In Malaysia, the government policy ordered qualified nurses working in nursing homes to support *other* health care settings during the pandemic, leaving care homes short of skilled staff (Hasmuk et al 2020).

There is relatively little information on how countries are working to re-enable access to external providers. Residential care settings in Germany have started re-enabling access to services such as hairdressers, physiotherapists, speech therapists and pastoral support (Lorenz-Dant 2020). In Malta, a complex protocol was put in place to enable the return of similar external service providers, covering common hygiene, PPE regulations and patterns of movement within buildings (Fenech et al 2020).

Visiting residential care settings in the Netherlands

The Netherlands have pursued a scientific approach to explore the impact of opening residential care settings for older persons to visitors. Local Area Health Authorities picked 26 care homes that proportionately represented nursing homes across the country and were allowed to 'expand the guidelines for visitors' (Verbeek et al 2020).

Findings from the research that accompanied the trial process showed that, while implementing the protocols and measures to enable one visitor per resident significantly increased the workload of staff, all participating nursing homes 'were unanimously positive' about the notable joy and wellbeing visitors brought to the residents. The care providers also reported that most visiting family members highly valued the opportunity to visit in person, even though limitations on physical contact and the opportunity to leave the premises of the nursing home were missed. Participating nursing homes also reported that in some cases residents were unable to recognise their family members, which was difficult for everyone involved.

While visitors and staff were concerned about the risk of transmitting or contracting COVID-19, only a small minority of potential visitors decided not to visit. Overall, care providers reported sufficient to good adherence to local guidelines. The authors reported that some deviations to local protocol occurred. For example, in some nursing homes it was permitted to share coffee or food. Wearing a mask for this was impractical (Verbeek et al 2020).

The substantial organisational and managerial task to prepare and supervise the visits were perceived as a barrier and several providers reported dedicating members of staff to the organisation of visits (Verbeek et al 2020).

Following this first phase policy makers concluded that it was possible for care settings to enable safe visiting practices. The Dutch government outlined 'roadmaps' to gradually reduce visiting restrictions. At first (25 May 2020) nursing homes could apply to regional public health authorities to be permitted to allow one fixed visitor per residents. By 15 June 2020, all nursing homes would be permitted to allow one fixed visitor per resident. In October 2020, the government passed the 'Temporary Measures Act COVID-19', which ensures that healthcare providers have the responsibility for ensuring that at least one 'family member or next of kin' can visit. It is also expected that residents, relatives and staff are involved in the decision-making process around developing a nursing home visiting policy (Kruse et al 2020).

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3.5 IMPACTS ON ACCESS TO AND SUPPLY OF HEALTH AND CARE SERVICES

The COVID-19 pandemic is having an impact on access to healthcare and care services for persons living in care homes.

Following bans on external service providers, some countries introduced telehealth visits and virtual check-ins from therapists (e.g. US, New Zealand; Van Houtven et al 2020; Ma'u et al 2020). A survey investigating medical assessments of care home residents conducted in 1,700 homes in Sweden found that contact with medical doctors was found to be insufficient, and one-third of care homes were unable to provide assessment and treatment of COVID-19 (Szebehely 2020). Access to hospital care for care home residents was also a concern raised in parts of Spain (Rodriguez Cabrero 2020; Zalakaín and Davey 2020); persons with disabilities were initially prevented from transfer to hospital, although that restriction was later removed. A later protocol sought to 'guarantee quality care', but also cautioned

that 'the sustainability of the health systems should not be endangered' (Zalakaín and Davey 2020). There were similar constraints to hospital treatment for care and nursing home residents in Italy, leaving some nursing homes operating effectively as 'COVID-19 hospitals' without support from appropriate healthcare professionals (Berloto et al 2020). In China, on the other hand, local emergency medical service plans were launched for persons living in care homes, including provision of healthcare services, medical equipment and medications (Shi et al 2020). The Netherlands have addressed this issue by increasingly organising their nursing homes in regional networks with healthcare organisations. This enabled better collaboration between nursing homes and hospitals during the second wave (Kruse et al 2020).

A further and widespread problem has been the lack of palliative care for older persons living in care and nursing homes (e.g.in Turkey and Sweden; Akkan and Canbazer 2020; Szebehely 2020). In Austria, new guidelines were developed to ensure provision of palliative care in situations where health care services had limited capacity (Schmidt et al 2020). In the German federal state of Baden-Wuerttemberg, guidelines recommended that advance directives, such as the refraining from artificial respiration, should be considered critically if a person develops severe COVID-19 symptoms, on the assumption that survival and recovery chances associated with COVID-19 infection may not have been taken into consideration when the document was initially signed (Lorenz-Dant 2020). There was criticism in New Zealand that individuals living in care homes were moved from their usual place of residence and died in hospital (Ma'u et al 2020). On the other hand, there have been reports of cases where older, vulnerable persons with serious underlying conditions were asked to sign 'do not attempt resuscitation' orders, which would mean that they would not receive care from emergency services should they become severely ill with COVID-19. These cases highlight the importance of careful discussions about advanced care directives with individuals nearing the end of life regarding their preferences (Iacobucci 2020).

Shortages of medication for persons living in mental health hospitals have been reported as a consequence of COVID-19 in some African countries, including South Africa and Kenya, because of slow global supply chains since March 2020 (Lopez Gonzalez 2020). Mental health professionals there expressed concerns about a 'shadow epidemic' of patients relapsing due to drug shortages (Lopez Gonzalez 2020). In addition, some community services used by persons with psychosocial disabilities have been stopped, with only emergency services available. Combined with restrictions on hospital admission, this has left many individuals confined to their homes or in overcrowded places, at risk of domestic violence and lack of support, leading to increased needs. Overcrowding in psychiatric hospitals in Ghana has been of great concern during the pandemic, despite some hospitals being praised for their response to COVID-19 by retraining staff on isolation, consultation and self-care measures, and hospitals procuring PPE (Gyimah 2020). The national mental health hospital in Kenya, Mathari Hospital, has stopped admissions and mental health professionals and advocates fear that this lack of access to services may lead to exacerbation of symptoms, or in extreme cases suicide.

Finally, one study investigated provision for children in residential care settings provided by NGOs across 14 nations primarily in the 'Global South' (Wilke et al 2020). In contrast to policies for older persons where residents remain confined in their care homes, government orders required children in residential care to be returned to their families. Whilst the authors argue for deinstitutionalisation of children's services, they also raise concerns about returning children to their families during a period of heightened economic pressures, without the usual support provided through schools, and with limited opportunities for caseworkers to visit and monitor children's wellbeing. In many situations, support structures that typically accompany this process cannot be provided during the COVID-19 pandemic. Pressure by governments on the NGOs providing the services meant that, in many cases, neither children nor families could be prepared for these transitions, leading to concerns about child safety and long-term family stability.

Many children with disabilities have had limited access to education during lockdown, and parents have had to cope with the additional pressure to support their children's education at home – additional task disproportionately carried out by women. Support provided to families has been variable, even in high-income countries. For example, in the UK, some schools for children with special educational needs and disabilities continued to operate during lockdown, some schools have supported families in distance learning, but some school have had no contact with pupils (Toseeb et al 2020; Pavlopoulou et al 2020).

INTERVENTIONS TO MITIGATE IMPACTS

Several countries have seen expansion of telehealth and other virtual services to enable access to skilled health care for persons living in care homes. In Lower-Saxony, Germany, 14,500 nursing homes were given tablet computers for regular remote medical consultations, and also to enable residents to make social calls (Lorenz-Dant 2020). Another response can be seen in Turkey, where the Ministry announced that the number of physicians based in nursing homes would be increased to ensure better health care provision of for residents (Akkan and Canbazer 2020).

CASE STUDY K

Remote counselling for a nursing home residents in Italy

Evidence from remote psychological consultations for residents of a nursing home in Rome has shown that some of the effects of visiting restrictions for external service providers can be mitigated with the help of technology.

In this case participants in the remote counselling programme were contacted by the psychologists for appointments through their personal mobile phone. For persons without their own device or for those who preferred video consultation, the nursing home provided the relevant equipment. The use of video-consultation was reported to be particularly helpful for persons with hearing impairment as it gave them the opportunity to read lips. It was also reported that persons with moderate to severe cognitive impairment benefited from video interaction. In some cases, initial support from staff was necessary and the head nurse provided participants with handouts for cognitive stimulations.

The findings of the report covered almost two months of remote psychological consultation services, in which 75% of persons usually in receipt of this service participated. It was found that individuals experiencing short-term memory impairment experienced difficulty in understanding constraints in social interactions and the psychological intervention could help to overcome 'feelings of being abandoned'. Others reported fear and anxiety for themselves but also their relatives (Renzi et al 2020).

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3.6 POTENTIAL LONGER-TERM IMPACTS OF COVID-19 ON RESIDENTIAL CARE SETTINGS

As we have seen, COVID-19 has had many and often severe impacts on older persons living in congregate care settings (especially in care homes and nursing homes). There is less evidence on other groups (children, adults with disabilities). Findings of the COVID-19 Disability Rights Monitor show that children with disabilities did not receive protection (e.g., in the UK, only adults were recognised as 'vulnerable' to SARS-COV-2) or support for their needs (including access to food, medicine, health care, education). In addition, the report highlights the special vulnerability of women and girls with disabilities, persons with disabilities who are homeless, and persons with disabilities living in remote and rural areas (Brennan 2020).

Several of these issues are linked to underlying concerns about how care needs are viewed by the general public and by governments, about connections between health and social (long-term) care sectors, as well as about the adequacy of regulatory arrangements in many countries (WHO 2020; Werner et al 2020). A report from Italy goes so far as to describe the neglect of social care as the 'original sin' (Berloto et al 2020). This is echoed in a report from South Korea that 'mass infection of older persons [in] long-term care facilities could have been prevented […] if the existing quality issues had been properly addressed before the pandemic' (Kim 2020).

As we have described in this section, steps to address infection prevention and management through strategic policy, often turned into guidance documents, have already been taken in many countries, even if – in the haste and unpredictability of the moment – there has sometimes been lack of clarity and insufficient attention to feasibility. But those policy and other responses too often damage quality of care, worsen quality of life and undermine human rights. We return to these issues in the next section.

Before that, we will simply note the growing realisation that 'while most people infected with SARS-CoV-2 either remain asymptomatic or recover quickly and completely, a proportion of infected persons develop persistent symptoms, which can be severely disabling' (Royal Society 2020; Carfi et al 2020). This syndrome is now being called 'Long Covid'. It appears that symptoms arise and abate in more than one physiological system, with often significant psychological and social impacts with potentially long-term consequences for individuals and society (Maxwell 2020). As far as we are aware, nothing is yet known about the prevalence of Long Covid among persons with disabilities or older persons, but the consequences for the locus and nature of care and support could be profound.

3.7 CONCERNS EXPRESSED BY EXPERT COMMITTEES, HUMANITARIAN AND HUMAN RIGHTS ORGANISATIONS

Expert committees, humanitarian and human rights organisations have started to reflect on the COVID-19 situation in congregate care settings in a number of countries. They have highlighted a number of concerns.

SOCIAL ISOLATION HAS CAUSED UNINTENDED HARM

A core policy of emergency management across countries was to ban visitors and to keep residents physically distanced from each other and from members of staff. While these policies aimed to protect residents from infections, they have been found to have 'resulted in unintended harm' with many residents experiencing loneliness, anxiety and depression (MSF 2020a). They may be particularly difficult to understand for persons living with dementia (Equality and Human Rights Commission 2020; Amnesty International 2020). Suspension of visits from family, guardians and care quality inspectors also means that there has been no external oversight of residents' wellbeing and safety (MITRE 2020; Amnesty International 2020).

A report from the US pointed to financial incentives for individual isolation practices. It described that care providers received higher reimbursement rates for moving residents with COVID-19 into individual isolation, instead of facilitating clusters with other residents who tested positive. This may go against residents' preferences of remaining with other residents with the same infection status (MITRE 2020). Médecins sans Frontières (MSF) and Amnesty International reported that indiscriminate, preventive isolation approaches have had detrimental effects on residents' health and dignified care (Amnesty International 2020). A greater number of residents in about 10% of Belgium care homes have been reported to have expressed suicidal thoughts and ideas about resorting to euthanasia (MSF 2020b). MSF also critiqued the absence of interventions to negative effects on residents' mental health as hardly any nursing homes in Spain provided residents with psychosocial support. MSF also recommended security measures that enable subdivisions to keep physical and community routines and therefore prevent social isolation (MSF 2020a). However, a lack of access to regular testing of staff and residents and transfers of persons from hospital to residential care settings, such as in England, hampered the re-introduction of small social communities within care homes (Amnesty International 2020).

BALANCED PERSON-CENTRED APPROACHES ARE NEEDED

Instead of top-down approaches, a US report recommended asking residents about their preferences and in cases where residents are unable to make these decisions, to include their legal representatives in the decision-making process. It urged the importance of recognising residents' lifestyle goals, such as residents' preferences on 'where they live, with whom they live, their quality of life, their visitor preferences, their desires, and ability to leave, and so on' (MITRE 2020, p. 67). Similarly, MSF advocated for a balanced approach 'between isolation, quarantine and communal living' that takes into account the 'comprehensive health of the residents' (MSF 2020a, p. 12). In Belgium, for instance, residents expressed their greatest needs to be 'contact with their families, visits, walks in the open air, physical contact and contact with other residents' (MSF 2020b, p. 22). Residents choices should be recognised and be part of the decision-making process (MITRE 2020). Amnesty International recognises that achieving the right balance is difficult, and it may have to be adjusted according to the development of the situation (Amnesty International 2020).

The pandemic as a catalyst to re-thinking care in congregate settings in Asturias, Spain

In many countries, the COVID-19 pandemic has brought to the surface long-standing concerns about the quality and appropriateness of existing care settings. For example, even prior to the COVID-19 pandemic, the government of the Spanish region of Asturias has been developing active and healthy ageing policies. The COVID-19 pandemic, however, has highlighted the urgency of the reforms. The plan emphasises community-based care and envisages gradual transformation of existing residential care settings shaped by the active involvement of key stakeholders, including older persons and persons with disabilities, as well as a public consultation.

Already planned are two pilot projects for persons with dementia. These new models will be established in existing large care homes but are designed to be more reflective of 'domestic homes' than care home settings. Each unit will house between 10 to 12 persons and will consist of private spaces (residents' rooms) and common spaces (living room, kitchen, dining room etc.) to facilitate social interaction and to enable individuals to pursue everyday activities. Staff working in these units will be trained to provide person-centred care and support that resembles a domestic environment, rather than rigid institutional routines (Martinez Rodriguez and Pascual Fernandez 2020).

This case study is based on Martínez Rodríguez and Pascual Fernández (2020)
and summarised by Klara Lorenz-Dant, LSE

ACCESS TO HEALTH CARE SERVICES

Access to health care services for a population where many have multiple health conditions has been disrupted during the COVID-19 pandemic. Amnesty International reports that in England there are cases where GPs had stopped in person visits to care homes and instead relied on phone conversations. In addition, hospitalisations figures of care home residents showed that in comparison to previous years, there were 11,800 fewer admissions in March and April 2020 (Amnesty International 2020). Also, in Spain and Belgium, not all care home residents had access to hospital treatment (MSF 2020ab). There is also evidence that some care homes were requested to add 'do not attempt resuscitation' (DNAR) forms to residents' files. Reports around these practices led the 'the British Medical Association (BMA), the Royal College of General Practice (RCGP), the Care Quality Commission (CQC), and the Care Provider Alliance (CPA)' to warn that DNAR forms should not be applied to 'a group of people of any description' and instead must 'be made on an individual basis according to need'. It is not clear what has happened with DNAR forms that have been added to residents' files 'without due process' (Amnesty International 2020, p. 26).

HUMAN RIGHTS IMPLICATIONS

Amnesty International pointed out that restrictive policies around visitors and social interaction with other residents and staff may violate residents' right to private and family life and to non-discrimination. In cases where these policies have led to a deterioration of cognitive abilities and mental health of the resident, 'they also violate the residents' right to health' (Amnesty International 2020, p. 47). Amnesty also warns that the practices preventing care home residents' access to health services infringe the rights to life, to the highest attainable standard of physical and mental health, to non-discrimination, and to freedom from torture and inhuman or degrading treatment (Amnesty International 2020).

4 BARRIERS AND RESPONSES

4.1 INSTITUTIONS THEN AND NOW

Congregate settings for persons with disabilities have a history stretching back more than one thousand years, motivated by a complex mix of well-intentioned care ('asylum' in the original sense of the word) and specialised treatment; economies of scale; social and private embarrassment; stigma and discrimination; social control and punishment. Whether out of convenience, inertia, altruism, safeguarding, prejudice, pecuniary interests, professional protectionism, perceived unaffordability or lack of political will, tens of thousands of these congregate settings across the world continue to operate today.

There is no doubt that a great many of these settings are 'institutions' in the way that we have defined them:

> Residents are isolated from the broader community and/or compelled to live together; … do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the residents' individualised needs.
>
> (European Commission 2009, p.9)

Given the abundance of evidence about how institutions blight the lives of the individuals who live in them, it is both astounding and scandalous how many persons with disabilities and older persons live in settings of this kind. As we illustrated in Section 2 with data for all age groups, across a range of disabilities and drawn from an array of countries, there are millions of children and adults accommodated in institutions today. It may well be that trends are generally moving in the right direction in some countries, with these numbers falling over time, but progress has been dreadfully slow.

Congregate living arrangements are not intrinsically bad, but there are countless examples of how congregate settings are or become 'institutional', with awful consequences for many of the individuals who live there. Those failings can be catalogued by reference to Article 19 of the CRPD. Institutions deny persons with disabilities the opportunity 'to live independently and be included in their communities and to choose where and with whom they live'. They do not support 'participation in the community'. They do not offer the necessary range of 'support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'. And community services and facilities accessed by the general population are not 'available on an equal basis to persons with disabilities', nor 'responsive to their needs'.

Children who grow up in institutions experience irreversible developmental damage, and their broader life-chances are very poor compared to family-based care. Adults who spend long periods in institutions often experience avoidable physical and mental ill-health, lack of stimulation and boredom. Some are subjected to physical, sexual or emotional abuse. Lack of autonomy, social isolation and loneliness are common. In short, both objective and subjective quality of life are poor – often appallingly so.

4.2 COVID-19

The COVID-19 pandemic has added a deadly further chapter to this depressing story, with above-average rates of infection and mortality in most kinds of congregate setting, and particularly in those for older persons. This is despite the efforts and commitment of staff in many congregate care settings to provide quality care. Imposition of greater restrictions on autonomy, choice and participation has further complicated the situation.

Most persons with disabilities, it has been argued, are not *inherently* at greater risk of COVID-19 infection or of severe illness or mortality as a result. However, many persons with disabilities have underlying health conditions associated with higher risks of severe symptoms or death (such as heart disease, diabetes or cancer). In part, this may be because of a history of previous, perhaps unavoidable, health behaviours (poor diet or limited exercise, for example) or because of poorer access to health checks and treatments compared to persons without disabilities (Center for Disease Control and Prevention 2020; UN 2020).

Added to these well-known long-term inequities has been rapid transmission of COVID-19 in settings where individuals live closely together, and where staff come in and out of those settings from their own communities (where infection levels may be high). These patterns place persons with disabilities and older persons at especially high risk of infection and mortality compared to the general population. The emerging evidence suggests that the risk of infections and deaths increase with the size of congregate settings. At the same time, some persons with intellectual disabilities or cognitive impairment find it hard to comply with social distancing or mask-wearing requirements, further exacerbating the situation.

On the other hand, arguments have sometimes been heard that it should be easier to manage infection-control in settings where there are skilled staff to oversee social interactions, personal hygiene and so on. There have also been attempts in high-income countries – through 'cohorting', isolation strategies, changes to the physical layout, restrictions

on visitors and external providers, and suspension of social activities – to try to reduce infection rates. Few of these approaches would be feasible in many LMICs, where provision is often more basic and informal, and where many facilities are not registered with any public authorities.

It has also been suggested that it is easier to control social contacts, for example by managing the flow of visitors (including family and friends) and services (food deliveries and medications, for example) into congregate settings when compared to the situation where persons with disabilities or older persons live independently in the community, especially during local or national lockdowns. However, as we have seen in the early months of the pandemic, virus transmission mechanisms were not sufficiently well understood, and many congregate care settings were not provided early enough with adequate PPE for staff, nor adequate access to tests. Those congregate settings became very dangerous environments (see Rajan et al 2020 for an account of the experience in England, and links in that paper to evidence from other countries).

As we described in Section 3, in countries with lower rates of COVID-19 infections at population level, care home resident deaths represented a lower proportion of all deaths. In some countries, admissions to congregate care settings were stopped, which may have left some persons in risky situations in the community, or alternatively stuck unnecessarily in hospital, in the sense of no longer needing the kind of skilled clinical care only available there.

Measures adopted to reduce infection risk in congregate settings themselves often proved damaging, by denying rights to self-determination, rights to health and rights to private and family life, social interaction and access to specialist medical treatment, for example. Mitigating measures included enabling regular phone calls, virtual meetings between residents and families, and 'window visits', but their consequences are unclear. Lack of palliative care for older persons living in care and nursing homes has proved to be another common issue.

Long-term care for older persons: Israel's response to COVID-19

Israel has a relatively young population; only 1.1 million of citizens are older than 65 years (12% of the total; OECD 2020). Most of long-term care is delivered to older persons living at home and in assisted housing facilities. The National Insurance Institute (NII) is responsible for long-term care services in the community, while the Health Plans (essentially managed care organisations) are responsible for medical treatment, including nursing care (NII 2020). In the beginning of 2020, 220,830 individuals of retirement age were eligible for publicly funded long-term care services at home.

In April 2020, 71,100 (2.1%) of older persons lived in 640 long-term care facilities (LTCFs); 49% were aged 85 or older. Most of the LTCFs are privately owned and funded, and include geriatric institutions (170), nursing homes (290) and assisted living and supportive housing (180; Statistical Abstract 2016).

As of 25 October 2020, most of COVID-19 deaths (84%) in Israel were among persons aged 65 or older. Out of 2,404 of total COVID-19 deaths, 861 (36%) were LTCFs residents. The severe outcomes of the outbreak in the LTCFs led to massive public criticism, as well as a 'cry for help' by the LTCFs. The slow response to COVID-19 in the LTCFs may have been due to the fragmentation of long-term care among three government bodies: the Ministry of Health, the Ministry of Welfare and Labour Affairs, and the NII. It was suggested that responsibility for LTCFs should be transferred to the Home Front Command of the Israeli army, despite its lack of experience in managing this type of event.

The LTCFs association submitted an Urgent Petition to the Israeli Supreme Court with the aim to increase COVID-19 testing for residents and staff in LTCFs, and to allocate an emergency budget to LTFCs for protective equipment and for recruitment of new staff and preservation of existing staff. Although the petition was rejected, the government appointed a national-level team to manage the outbreak in LTCFs and a national project 'Fathers and Mothers Shield' was initiated in April (Tsadok-Rosenbluth et al 2020), and included:
• establishing a single headquarters to coordinate government efforts;
• expanding the Home Front Command's role;
• establishing COVID-19 patient care departments in each facility;
• prohibiting staff from working in more than one facility;
• allowing family members' visits in special cases and subject to social distancing directives;
• increasing technological means for both residents and staff;
•i ncreasing the scope of COVID-19 testing in LTCFs.

The implementation of extensive testing was seen as the most important policy of the program. In October 2020, 10,000–15,000 daily tests were carried out in LTCFs. Less successful policy was converting regular LTCFs beds to COVID-19 beds; only 40% of the state's target has been achieved. The Ministry of Health invested massive resources in LTCFs. By August 2020, the cost of protective equipment distributed to LTCFs was NIS19.2 million (£4.4 million; Tsadok-Rosenbluth et al forthcoming).

Changing the balance of support from institutional care to community-based services
At the start of the pandemic, older persons living in the community were treated with paternalism; they were viewed as a 'risk group' that must be protected, which caused concerns for families. There were calls to impose a special quarantine on older persons living in the community. However, after the first national lockdown, no special restrictions were imposed just because of age, but the message of policymakers was clear: cautious care should be taken of older persons to reduce risks of infection.

The Ministry of Defence and the authorities developed a project with the aim to maintain public health and prevent infection in the community by providing assistance to persons in need, for example, to isolated or unwell individuals, independent seniors, youth, and other at-risk groups; any resident can reach the program directly. It has started in 'at-risk' cities, mainly cities with high concentrations of Arabic and ultra-Orthodox populations. Each city was divided into neighbourhoods and each neighbourhood has built a 'community assistance envelope' tailored to its residents, with support from the Home Front Command of the Israeli army. To date, 138 cities have been included in the project. The situation in small localities is more complicated; usually an intervention is provided only in case of a COVID-19 outbreak.

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4.3 BARRIERS AND RESPONSES

Why, then, are so many persons still living in institutions? There are numerous barriers, many of which we have mentioned already in this report. Here we consider them together under the following headings:

- Stigma and discrimination
- Stages of institutionalisation
- Limits on family and other community-based care

- Business and professional interests
- Relative costs
- Funding flows
- Few opportunities to make choices
- Lack of political will

We also look at some of the solutions suggested to avoid or circumnavigate these barriers.

STIGMA AND DISCRIMINATION

Underlying many of the barriers listed above is widespread lack of awareness and poor understanding of disabilities, pervasive stigma and prejudice, and deep-rooted discrimination. Awareness-raising is key in overcoming outdated understanding of disability and negative attitudes towards persons with disabilities. Article 8 of the CRPD includes States' obligation:

To raise awareness throughout society, including at the family level, regarding persons with disabilities, their capabilities and contributions to society, and to foster respect for their rights and dignity.

The Report of the Office of the UN High Commissioner for Human Rights on Article 8 provides guidance on a human rights-based approach to developing awareness-raising programmes for governments to meet their obligations under international human rights law (UN A/HRC/43/27 2019).

Reasons for stigma, which can often lead to neglect and discrimination, are familiar.

People perceive human differences and label them, with those 'labels' associated with socially undesirable, even despised characteristics. Labelled persons are seen as a distinct group to be marginalised or excluded. Emotional reactions include fear and disgust in relation to those excluded individuals, while those persons who are being labelled often feel shame, embarrassment or humiliation. Families may feel stigmatised by having a member with a psychosocial disability or dementia, and keep them confined to the house, locked in a room or abused in other ways (Teka and Adamek 2014; Evans-Lacko et al 2019). Discrimination is an inevitable consequence, with labelled persons denied participation in activities available to the rest of the population, leading in some cases to incarceration in institutions: 'shunned' as Thornicroft (2006) summarises it.

There is also the commonly occurring problem of self-stigma among labelled individuals, who see themselves as 'less worthy' or 'not good enough' to participate in activities enjoyed by the general population. Self-stigma adds to the damage

that individuals already experience because of the attitudes of others. Research in the mental health field, for example, shows an association between societal levels of stigma and both unemployment (Evans-Lacko et al 2013) and suicide (Schomerus et al 2014).

Indeed, the mental health field provides insights into ways to address stigma and fight discrimination. A multi-faceted strategy can bring about change: building awareness across the population (for example through national engagement programmes), combined with empowerment and engagement through local events, led by persons with lived experience of psychosocial disabilities. Social contact of this kind, when undertaken creatively, has been shown to be effective, even if change is slow (Thornicroft et al 2016). Successful collaboration of health and social care services, coupled with public engagement programmes, can be illustrated by transformation of psychiatric services in East Lille summarised in Case study N (Roelandt et al 2014).

More generally, looking across all groups of persons with disabilities and older persons, it is often a lack of awareness that unwittingly reinforces negative attitudes. Llolyd-Sherlock (2020) in a recent blog, lamented how the United Nations World Data Forum had published some excellent discussion pieces on a range of issues, such as gender, racial and ethnic groups, as well as persons with disabilities and 'institutionalised groups', but made no mention of older persons. Of course, this is just one blog on one website, but it reflects a common lack of awareness, in this case of the awful statistics that were already being reported in many countries about how older persons in care homes had been dying in hugely disproportionate numbers.

The first barrier, then, is prejudice against persons with disabilities and ageism, and hence a lack of societal commitment to change the situation.

CASE STUDY N

Transforming care for persons with psychosocial disabilities from hospital to community in East Lille, France

East Lille has a population of 86,000 and with significantly more disadvantage compared to the French national average: it has the shortest life expectancy in France, a high rate of tobacco or alcohol related deaths, and higher unemployment rate than average. In 1975, East Lille was served by a 300-bed psychiatric hospital which consumed 98% of the mental health budget. There was no physical or social connection with the community. Since then, East Lille has developed 'a community response to a community challenge'. Care for persons with psychosocial disabilities has been reorganised into to an almost outpatient-only service in the community, with an open ward of 10 beds near a general hospital. The average hospital stay decreased from 213 days in 1971 to 7.5 days in 2012, whilst the number of persons receiving support increased from 589 to 2,798 (Roelandt et al 2014).

This transition required significant investment of time and resources into community involvement, including anti-discrimination and anti-stigma initiatives. Art, culture, and community inclusion are at the heart of all practice. The aim is to maintain integration with the community even during crises.

Mobile service teams have been established with rapid response and fast referrals, enabling persons to get help quickly, with multiple routes to access services and more than 13 consultation sites. Health and social care services work in close partnership, and include general practitioners, pharmacists, social workers, community nurses and user-led groups. Nurses and psychiatrists are available 24/7 and will respond with a home visit if necessary (Crepaz-Keay et al 2015).

The service team meet daily (physically or virtually) and discuss the most pressing issues; urgent actions are executed immediately. The team maintains a single 'risk' spreadsheet with live information on everyone in contact with the services. Non-urgent issues are addressed within days rather than weeks or months.

Together with the municipality, several housing options have been developed: therapeutic host families (an alternative to hospitalisation for persons in acute situations); a crisis house (for short, high-intensity support); associative flats (most are shared between two or three tenants and a student; some are sheltered flats for tenants with severe problems, staffed 24/7 by care or health education assistants). Some flats are part of social, low-rent accommodation, some are used for transition to another type of accommodation. Tenants are supported by multidisciplinary mobile teams who provide medical, social and educational support; psychiatrists and nurses provide regular therapeutic activities and consultations.

All services are open, and no one is compelled to accept treatment. The small new ward does not look like a psychiatric hospital. It has a calm, cultural atmosphere and treatments resemble a spa. The emphasis is on physical and mental wellbeing, not on symptoms and illness.

The services in Lille provide a concrete example of what can be done in the real world with imagination, commitment, and a long-term view (Crepaz-Keay et al 2015).

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STAGES OF INSTITUTIONALISATION

In some countries, it could be said that institutionalisation is just beginning; for example, in China, there has been a rapid expansion of care homes to provide long-term care for older persons (see Case study B), but new institutions for persons with a range of disabilities and needs are springing up across much of the world. In some LMICs, governments have only recently begun to address the needs of persons with disabilities, and many have chosen to invest relatively heavily in congregate living settings for some of the reasons set out above, such as the opportunity to make best use of scarce specialist resources or to safeguard persons with care needs, or perhaps because family support is not available (see below). In some cases, these new institutional settings have been funded by other governments, international donors, private companies, and even international bodies such as the World Bank.

Governments or other providers might therefore be reluctant to jettison their new investments. But even in some high-income countries, where institutions are clearly not new, they are still seen as an appropriate way to care and protect persons with disabilities and older persons. For example, France is among the few EU countries where the number of segregated facilities has *increased* over the last decade: institutions for persons with disabilities are presented as 'innovative platforms' and perceived as a major social achievement (European Network on Independent Living 2020; Siska and Beadle-Brown, 2020). In the

US, vested interests in the land, buildings and companies that operate 'nursing facilities' for older persons are used to lobby at state level against home-based services. States have been the target of the US Department of Justice for the unnecessary institutionalisation of individuals with disabilities, and the lack of community service provision. For example, a recent settlement agreement with the state of North Dakota ensures that individuals with disabilities and older persons will have a choice as to where they live, including in their own home (US Department of Justice 2020).

A challenge in some LMICs – partly because of the 'newness' of provision, in turn linked in part to the relatively recent growth in needs (linked to population ageing, for example) – is that a lot of congregate care is unregulated, unmonitored or operating in the shadows of informal private transactions (Browne et al 2020; Sasat et al 2020; Rajagopalan et al 2020; Amour et al 2020). Consequently, pursuit of a deinstitutionalisation policy is severely hampered by simply not knowing anything about the residents or the circumstances in which they are accommodated. This is linked to a more general lack of information on persons with disabilities, in turn stemming from a societal lack of awareness or concern.

Where systems of registration have been introduced, governments need to make better efforts to enable and encourage previously unidentified providers to register

their services. The *CIAT approach* – coordinate, identify, assess and risk-rate, and targeted support – may be a useful framework to support such a process (Lloyd-Sherlock et al 2020). It could also help if a single government body (such as a ministry) took overall strategic responsibility for the sector, with a clear regulatory mandate and sufficiently resourced structure to support improvements in quality of care, investment in staff development and promotion of the rights of persons with disabilities.

A view often expressed in high-income countries that started processes of deinstitutionalisation a few decades ago was that many persons living in congregate settings would continue to need specialist treatment and care that would not easily be provided in the community. An argument voiced against deinstitutionalisation of individuals with severe psychosocial disabilities, for example, was that they might be more prone to crises or symptomatic relapses in the community, which would then require re-admission to in-patient settings. Of course, investment in preventive and crisis-response services in the community would help to avoid such re-admissions, but if those hospital stays were appropriate, therapeutic and (hopefully)

short-term, this 're-institutionalisation' argument holds less water.

Some long-stay hospital and residential settings aim to provide for a range of medical needs, and some arguments heard against deinstitutionalisation are that persons with disabilities would then be needing to use 'mainstream services', which would need to expand. Of course, this is *exactly* as it should be if persons with disabilities are to exercise their rights to participate in activities and use services that are routinely available to the rest of the population.

If investment in community support is inadequate, even in countries with advanced deinstitutionalisation policies, there is a risk of 're-institutionalisation', for example, in hospitals and community-based care homes for persons with longer-term and complex needs and those with a history of contacts with the criminal justice system. Placements may be geographically distant from home or family (sometimes called 'out-of-area treatment') causing social dislocation, concerns about care quality and poor co-ordination of systems for addressing individual needs (Caldas-de Almeida and Killaspy 2011).

LIMITS ON FAMILY AND OTHER COMMUNITY-BASED CARE

Many persons with disabilities who live in community settings rely on family members or friends to support them in a range of activities of daily living. Family members are often best-placed to understand the strengths, needs and preferences of persons with disabilities, and also in a good position to protect and promote their rights under the CRPD. If suitable community-based services are developed and accessible, the combined skills and efforts of persons with disabilities, families and community resources can undoubtedly ensure better quality of life than experienced in institutional facilities.

However, this is not always achievable, perhaps because there are no family members or friends available to be carers, or at least not sustainably for long periods. Trends in many high-income countries over recent decades have been towards smaller families, greater geographical mobility,

higher female labour force participation rates, longer life spans for persons with congenital disabilities, rapid population ageing, and shifting ambitions held by individuals about their lives. There has also been growth in the phenomenon of 'sandwich carers', where persons in their middle age (especially women) are expected to provide care for both parents and grandchildren, as a consequence again of changing demographic and employment patterns.

In many LMICs, similar trends can be seen, although usually starting a few decades later than in high-income countries. Observation of weakened extended family support in Sub-Saharan Africa, for example, has created challenges for provision of care at home (World Health Organization 2017). Certainly, the migration of younger persons from rural to urban areas, often long distances away (perhaps abroad), has created a shortage of carers for persons

with age-related needs, for example. There are now attempts in some countries to attract younger persons back to rural communities to work as care staff, but of course this requires injection of new funding.

Strains experienced by family and other carers must be taken into consideration. Being a carer can lead to long-term economic disadvantages, particularly from forgone education or employment and out-of-pocket expenses (World Health Organization 2017). These and other opportunity costs of being a carer can be high, especially in rural societies. Some carers, such as those supporting persons with dementia, experience above-average rates of depression and anxiety. Carers play pivotal roles in preventing or delaying admission into care homes or hospitals, particularly if individual needs change over time, as with a complex condition such as dementia (Verbeek et al 2015; Cepiou-Martin et al 2016), so supporting them to cope with their challenging role is imperative.

There is evidence of what can work to support carers. Effective approaches include partial 'replacement' care (i.e. supporting community services), flexible working conditions, support groups, and interventions based on psychological therapy, training and awareness-raising (Brimblecombe et al 2018). Greater use of information and communications technology could help, although available evidence on effectiveness and acceptability is still relatively weak. The care of persons with disabilities is personal and inherently relational. Many older persons living in their own homes, for example, are reluctant to see their face-to-face visits from community nurses or home care workers replaced with remote monitoring devices or telemedicine, not least because the visits of health and care staff provide welcome human contacts in what might otherwise be isolated lives.

Effective supports for family and other carers require commitment of resources by the state or some other source, and a structure within which to deliver them, although some are undoubtedly economically attractive in that initial investments lead to compensating savings in due course (Livingston et al 2020a). Needs for carer support can change over time, either because a person with disabilities has a degenerative condition which affects the intensity and/or domains of need, or because the ability of the family or other carer itself changes because of their own health or other circumstances. Indeed, among older couples, the roles of carer and cared-for person will often switch over time as respective needs change.

Family and other carers have rights too, including the right to choose where and with whom they live, to have the opportunity to participate in paid employment, to enjoy good health, and so on. These rights may be threatened by societal expectations that families will always support persons with disabilities. Because caring is still heavily gendered, hegemonic expectations of this kind fall heavily on women, and the tension between these different sets of rights can lead to substantial inequities.

During the COVID-19 outbreak, family carers saw support disappearing overnight, particularly day centres and short breaks services, and were left feeling that they 'had to make up the shortfall' (Towers 2020). Many carers struggled to cope with supporting their loved ones, with detrimental consequences for their own mental and physical health and their relationships. Some families remain at home providing 24-hour support to their relative; some with the additional stress of trying to work from home or not being able to return to work because of their caring responsibilities (Lorenz-Dant and Comas-Herrera 2021). All these factors have led to a great deal of anxiety and trauma being experienced by both persons with disabilities and their family carers. There is a sense of deep worry about the future, in terms of their relative and themselves getting back to where they were before COVID-19 (Towers 2020).

BUSINESS AND PROFESSIONAL INTERESTS

There are many countries where a high proportion of public funding is committed to the (relatively) small number of persons in institutions (Shen et al 2017; Crowther 2019). That is not a sustainable argument for retaining those institutions, but it points to the challenge of shifting resources to community services, particularly if there is also the perception that community-based services are 'too expensive' (see next subsection). Paradoxically, some low-income countries tend to place more children with disabilities in institutions than do high-income counties (Mulheir 2015).

The high proportion of funding allocated to congregate settings has historically often been reinforced by funding or reimbursement mechanisms in the wider health or care sector. In a universal healthcare system with top-down budgetary allocations from central government, large hospitals were traditionally funded directly in some countries, with their budgets growing incrementally year-on-year without much regard for performance. In England, it was only when that funding route was changed so that resources were instead channelled to local health bodies that then decided whether to transfer money to the hospitals that genuine economic incentives were introduced to re-balance care between institutions and community.

In some insurance-based health systems (whether social or voluntary insurance), treatment and care have sometimes *only* been reimbursed in congregate care settings, with community services being excluded; this is still the case in parts of the US, for example. (Indeed, to receive care funding in some US states, young persons with disabilities live in care homes for older persons.) With *fee-for-service* reimburse-ment mechanisms, there is a strong incentive for the provider to maximise what they deliver, which then encourages providers of congregate care to keep their places filled by accepting admissions and slowing down movement back into the community.

Two further examples can be given of stakeholder interests that work against deinstitutionalisation. One is something mentioned earlier, where external funding from foreign governments or international agencies has been transferred on the wrong premise: to replace, for example, a decrepit long-stay psychiatric hospital with a *new* long-stay psychiatric hospital, rather than seizing the opportunity to invest in community care. For example, in the Czech Republic, more than €5.6 million of EU funding was spent on children's homes and institutions for persons with disabilities between 2008 and 2012 (Lumos 2015). However, despite this expenditure and the intended 'humanisation' of institutions outlined in the Czech deinstitutionalisation strategy, bad practice persists and persons continue to live in institutions (Parker and Bulic 2016). Relatedly, the lack of legal frameworks encompassing new community-based services in many countries creates a 'perverse incentive' in favour of placing persons with disabilities in institutions, instead of providing them with the support to live in the community (Parker 2010). It really ought not to be so complicated to co-ordinate actions across government and international agencies to avoid such outcomes.

Second, congregate care settings, for example for children, are 'popular with governments, donors and organisations keen to show "results"' (Csaky 2009, p.11), whereas family-based care is seen as more complex and difficult to communicate (Lerch and Severinnson 2019). Institutions provide employment to a large number of persons – an issue to which we return in a moment – as well as a fundraising model for many organisations which is often based on the number of resident children (Csaky 2009):

> A brightly painted orphanage filled with children can often leave a more positive impression with a Western donor than the image of a child in a local foster family living in humble surroundings in sub-Saharan Africa.
>
> (Csaky 2009, p.12)

In responding to COVID-19, new guidelines and novel service designs have been introduced to congregate settings to protect residents' lives, but they may not – as we have described earlier – actually *improve* quality of life, because they

introduce further restrictions on social interaction, movement within the facility, visitors from outside and impersonal care from staff wearing PPE. At the same time, these measures are likely to increase the cost of residential care (Comas-Herrera et al 2020; Werner et al 2020). This is because of a need to purchase PPE, for example, to bring in extra staff to cover for absences, and perhaps expenditure on changes to the physical layout of the premises. Moreover, public perception of risks associated with congregate care may have changed, leading to reductions in demand (Forma et al 2020), which may threaten the business model for private sector providers. Care homes in many countries, including Malaysia, felt the effect and experienced challenges in paying their staff due to dwindling numbers of residents (Hasmuk et al 2020). Concerns around financial viability have also been raised in relation to nursing homes in the US (Van Houtven et al 2020; Werner et al 2020).

The combined consequence may be that care home places become unavailable or unaffordable for persons without access to community-based care or without family members to provide unpaid support. At least in the short term, financing mechanisms will be needed to support and protect individuals in need of congregate care to address inequalities in access. In the longer term, of course, funding models are needed to create the right incentives to develop high-quality services in the community.

A fear expressed by some professional groups, such as psychiatrists, is that closing a large hospital would mean that resources currently committed might not be transferred to community services. Instead, released funds could 'leak away' to other parts of the health system or

economy. There is a difficult balance to strike between protecting resources to support a particular group of persons with disabilities, albeit in an inappropriate setting, and simply reinforcing a discredited rights-denying model. The issue is slightly complicated by the fact that the community-based services needed to replace an institution will probably require funding from multiple budgets. We come back to this 'silo-budgeting' challenge below, but the issue is whether resistance to deinstitutionalisation is based on enlightened protection of an existing budget or more self-serving protection of jobs or power. The culture of institutionalised care is resistant to change (Krupchanka and Winkler 2016). Individuals involved in managing and maintaining institutions have an interest in preserving the current system for several reasons, such as potential loss of job and status, and not believing that persons with disabilities have the right to live in the community (Parker 2010).

A related issue, and – in the short-term at least, an important barrier – is that large congregate care settings are major employers. The historical tendency in many countries to locate large institutions outside of the main centres of population means that often a high proportion of the jobs available in an isolated community will disappear once an institution closes, a concern that has recently been expressed in the former USSR (van IJzendoorn 2020; Lumos 2015). In other countries, trade unions have been known to oppose deinstitutionalisation. In planning the closure of a large source of employment, therefore, local and national stakeholders will need an economic regeneration plan, perhaps identifying alternative uses for institutions and certainly creating new employment opportunities.

RELATIVE COSTS

The overwhelming justification for deinstitutionalisation is to provide persons with disabilities and older persons with better quality of life. But that provision needs to be affordable within the context of funding systems and policy commitments, themselves dependent on societal and political will to effect change. A barrier to deinstitutionalisation sometimes suggested is that the alternatives to congregate care

settings are 'too expensive'. This is based particularly on arguments that grouping persons together reaps the benefits of economies of scale. As discussed in Section 2.6, available evidence on relative costs is mixed, and anyway complicated by the fact that some previous studies have not been designed sufficiently well to offer credible evidence. What is clear, however, is that in a *good* care system, the costs of

supporting dependent individuals are usually high *wherever* those persons live, and policy-makers should not expect costs to necessarily be low in community settings.

However, and again as discussed in Section 2.6, there is more than one issue to be addressed here. One of those issues concerns this perceived affordability of different options for supporting persons with disabilities and older persons. Another is cost-effectiveness: whether a higher cost option is considered 'worth it' in the sense that the effectiveness gains (such as better quality of life) are sufficiently large and important to justify allocating the additional resources.

Community care is a matter of marshalling resources, sharing responsibilities and combining skills to achieve good quality modern services to meet the actual needs of real people, in ways those people find acceptable and in places which encourage rather than prevent normal living… This requires the better use of that proportion of… resources which is now locked up in the hospitals. A good quality community-oriented service may well be more expensive than a poor quality institutional one. The aim is not to save money: but to use it responsibly.

(UK Government 1985, pp.1–2).

Whether an option (for example community-based care) is considered to be 'cost-effective' is a value judgement: it reflects how much decision-makers

(representing society as a whole or a health insurance fund) are willing to pay for services in order to achieve the better outcomes. But even if an option is cost-effective, it may still be unaffordable because there is insufficient money in the budget to pay for it, or an insufficient number of suitably skilled staff available to deliver it. We come back to some related issues in the next sub-section. To state the obvious, committing more resources to one area means taking them from another, and those opportunity costs may or may not be considered 'too high'. In addition, there are considerable inter-individual differences in the costs of providing care for persons with disabilities, linked to individual characteristics and circumstances, and to the community or country context: some persons will be able to live independently with very little support, while others may need 24-hour care. Any deinstitutionalisation policy will need to recognise and respond to inter-individual differences of this kind in order to optimise support, and to avoid exacerbating inequalities in access and outcome.

We discussed earlier the pressures felt by some family or other carers, or indeed the absence of any suitable individuals to fill those roles. The lower the availability of unpaid care, and therefore the greater the need to rely on paid staff, the more challenging it can be to find cost-effective and affordable community options. If in the future, availability of unpaid care declines relative to need (as most projections suggest will happen), the economic case in support of community-based options may weaken. Economic criteria should not, of course, dominate decisions, but clearly cannot be ignored.

FUNDING FLOWS

The balance between institutional and community services as a national, regional or local policy aim *has* undoubtedly been influenced by economic considerations. In a number of high-income countries, it was often noted that the large institutions were expensive to run, and indeed many were operating in run-down buildings requiring substantial capital spending. Cost and cost-effectiveness arguments were therefore used to support a shift in the locus of care. However, even if it was the case that

resources tied up in institutions would be sufficient to fund high-quality community care – and the evidence on that is equivocal, as we have just noted – there is a complicated, drawn-out and not always uncontentious process needed to release the resources tied up in institutions and to make them available for community support (Knapp et al 1997).

One consideration already mentioned is that the budgets used to fund institutions

may not be ring-fenced to support development of community services, something that proved to be a justified fear in some hospital closure programmes in high-income countries a few decades ago.

Second, to avoid catastrophic consequences, such as those seen in South Africa (Case study O), institutions of whatever size cannot be closed 'overnight' without first ensuring that adequate community services are in place. Investment in community services (including the recruitment and training of staff) needs to be generous enough and early enough in the process of changing the balance of provision to avoid adverse consequences such as homelessness, increasing use of restriction orders, imprisonment and community opposition (Priebe et al 2008; Skokauskas et al 2020).

Third, 'bridging funds' or 'double-running costs' will be needed during the period in which community-based arrangements are being expanded and institutional care is being closed down. It is often only when a large institution has *fully* closed that all of the budgetary savings are secured. Policy-makers at different levels of government must be prepared to commit both pump-priming and ongoing funding to achieve successful deinstitutionalisation.

A related challenge is one we have mentioned already: institutions generally operate with a single budget, with relatively few costs falling to service providers outside that setting. In contrast, good community-based care could bring together the skills of a diverse mix of services (health and social care, housing, welfare benefits, employment support, leisure and so on), usually with a number of different organisations and budgets involved. Co-ordinating across those budgets is imperative to avoid 'silo problems': these could include gaps and inconsistencies in support, as well as wasteful duplication. If we link this to the previous point that the benefits from investing in community-based care may only be fully apparent after

a few years, policy-makers are faced with what the pernicious 'diagonal accounting' problem: spending in one sector has knock-on impacts in *other* sectors, perhaps with significant time-lags. This might be quite a strong disincentive for a government whose time horizons are tied to electoral cycles (Knapp and Wong 2020).

Some of the economic impacts of deinstitutionalisation might not be immediately visible, such as those falling to families and other carers. Again, this is something already discussed. Although less 'visible' in some sense, these effects may nevertheless be pivotal in shaping decisions and generating quality of life. For the reasons outlined earlier, it would not simply be naïve, but dangerous, for governments to assume that families can always be relied upon to be frontline carers.

There are many possible responses to these funding-related issues (EU FRA 2017b). One is obviously the need for long-term service planning and financial commitment: successful deinstitutionalisation cannot be a 'quick fix'. In turn, this requires policy that looks beyond the electoral cycle. Linked to this is the urgent need for coordination across multiple policy areas: not just health and social care, but also education, employment, housing, criminal justice, poverty alleviation, social security (welfare benefits), community development and immigration (see, for example, Shen et al 2017; Caldas-de Almeida and Killaspy 2011; and Case study N). Structurally, this could involve some kind of joint planning or joint commissioning to bring together two or more budget-holding agencies, or devolving certain powers and responsibilities to case/care managers, or to individual persons with disabilities themselves through personal budgets (see next subsection). Coordination – of ambitions, resources and actions – is also needed between individuals, their families, their neighbourhoods and communities, and commercial and charitable organisations in their locales.

Deinstitutionalisation in South Africa: the Life Esidimeni tragedy

During colonial rule, countries in sub-Saharan Africa introduced psychiatric institutions to care for persons with psychosocial disabilities (Saxena and Maulik 2003). However, following independence these countries did not proceed to deinstitutionalise the hospitals, as was done in the US and parts of Europe in the 1960s and 1970s. Today, discussions surrounding deinstitutionalisation are taking place. However, there are numerous barriers to deinstitutionalisation in LMICs, such as human resource shortages, stigma, and a lack of funding and adequate community-based services.

In 2002, South Africa committed to protecting and promoting the human rights of persons with psychosocial disabilities by adopting the Mental Health Care Act (Lund 2016). Both policy and legislation advocate for community-based provision of mental health care; however, psychiatric hospitals dominate as the main mode of service provision (Lund et al 2010).

South Africa provides a unique example of how deinstitutionalisation can go wrong if there is no adequate planning by the government. This was illustrated in the Life Esidimeni Tragedy that took place in 2015 when the Department of Health made the decision to cut funding for the 2000-bed facility that accommodated adults with a diagnosis of schizophrenia, Alzheimer's disease, bipolar disorder and other long-term conditions (Lund 2016). The residents were released into the care of NGOs that were inadequately resourced, which led to the death of 37 persons (Lund 2016). This tragedy illustrates the risks of moving towards deinstitutionalisation even with planning. 'The tragedy occurred despite the fact that the Department of Health had commissioned and adopted a study on optimal norms of community-based mental health care in South Africa.' (Lund 2016, p. 404).

Following this tragedy, the National Human Rights Commission established a panel to review services for persons with psychosocial disabilities in the country and compiled strong recommendations to inform services in primary care and community-based organisations. Additionally, the Department of Health increased surveillance and made regulations for NGOs providing community-based services for persons with psychosocial disabilities. A concern has been raised by advocates that these restrictions are so stringent that it costs large amounts of resources for NGOs to prove that they have certain facilities in place. This leads to the closure of NGOs, or provision of underground services in order to get around the regulations.

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FEW OPPORTUNITIES TO MAKE CHOICES

Perhaps the biggest barrier to deinstitutionalisation is that decision-makers simply do not listen to the views or act upon the preferences of persons with disabilities and older persons. This may be out of ignorance, stigma or prejudice; or the assumption that those persons are incapable of holding valid views or expressing meaningful preferences; or because it is thought that the views of other persons (such as health or care professionals) are more relevant. These tendencies have been seen in societies for millennia.

Whilst it is true that individuals experiencing, say, an acute psychotic episode, or seeming confused and agitated in the later stages of dementia, or greatly limited in their cognitive skills, may struggle to express their preferences for how they live their lives, there are still ways to try to engage with them. These include an array of communication devices, advance directives, advance treatment plans, supported decision-making and so on. Advocates and supporters who build up close relationships with persons with disabilities over time can also help to interpret and channel preferences.

In making their decisions, a person with disabilities or an older person may choose to live in a congregate setting. For example, some older persons may decide – in full knowledge of the options open to them, and

without coercion – that they would like to move into a care home. In doing so, it is important that they have a genuine range of options open to them: for example, a range of different care homes from which to choose, or full appreciation of what community-based alternatives might be available. The challenge for many older persons, however, is that their move into a care home may be precipitated by a crisis, such as a traumatic event like a fall leading to a complex fracture, or the death or serious illness of a family member or carer. In such hurried circumstances, fully informed choice may be unattainable. Nevertheless, any such decision for an 'emergency admission' should not be irreversible.

This calls for a more nuanced approach, driven by the right to choose. Some older persons may simply feel safer in a congregate living setting, or less socially isolated, or less of a 'burden' on their families (which is a remark often heard), particularly if their needs for care have become deeply personal. Over the life course, individuals may hold different views about who should provide personal, often quite intimate care. What is acceptable when undertaken by a nursing assistant in a clinical setting might feel very different when undertaken by an adult child in the person's own home. What is acceptable to someone at age 3 is different from what is acceptable at age 13 or 43, but may, for some individuals, become acceptable again at age 93. Someone who has grown up with a disability may feel differently about personal care tasks compared to someone who, as a result of traumatic brain injury, is suddenly physically disabled in mid-life. There may also be differences in preferences between someone whose needs for personal care are fairly stable over time and someone with a degenerative condition.

In other words, persons with disabilities and older persons should be supported to make informed choices about where they live, with whom they live, how they engage with services, how they approach end-of-life and so on. Older persons may freely choose age-restricted retirement housing or sheltered accommodation, or a care village, or specialist 'extra-care housing' (where services and care are available on-site; Housing LIN 2017). These and other options may allow ageing in place, where

someone is able to live in the home and community of their choosing as they age: support available to them adapts as their needs and preferences change (Wiles et al 2012). These are not inexpensive settings, however, and may be unaffordable to many individuals without public support (Lum et al 2016). If governments are to support such an approach, they may need persuading that the quality of life improvements that are generally experienced justify the higher costs (Jutkowitz et al 2011). It is especially important to remember at this point that the 'decision-makers' in this and related contexts will very often be older persons themselves: long-term care is very often directly funded out-of-pocket or via privately arranged insurance paid for by individuals and families (Colombo et al 2011).

AGE Platform Europe (AGE), the largest EU network of organisations of and for older persons, representing over 40 million individuals, summarised its views on how independent living could be achieved for older persons with impairments and functional limitations:

The majority of older people wish to continue living at home. However, where community supports are limited or homes are not adapted to individual needs, there is no option but for older people to enter residential care or depend on their family. Home care is not always a statutory entitlement and older people do not have an automatic right to choose a care setting. This leads to inadequate resources and barriers to living in the community.

Some older people (for example those without close family or social network) wish to have the option to reside in a care home where they can avoid the isolation, loneliness and feeling of unsafety of living alone, while continuing to live autonomously. Such arrangements represent for them 'living spaces' where they can socialise with peers, access leisure and personal development activities as well as adequate services by trained professionals– such as tailored support for people with dementia.

> Adapted living places can empower older people with functional limitations manage their own household and decide how to live their day to day life. The Independent Expert highlights that living in residential settings can be an autonomous decision of the individual that should be respected. In addition, nursing homes may deliver some 'community support services' for older people living in the surroundings. The process of 'deinstitutionalisation' should not deprive older persons of these options, as long as user control and high quality of services are enabled without limiting liberty, privacy, independence or leading to segregation.
>
> (AGE Platform Europe 2016, p. 3)

Evidence that smaller non-traditional nursing homes have experienced lower infections and mortality rates (Zimmerman et al 2021) may give impetus to an already existing push towards less institutionalised approaches to congregate care in smaller settings (Rostgaard 2020; Martinez Rodriguez and Pascual Fernandez 2020). The general point to reiterate is that institutionalisation is defined by the *social* environment of a setting, and the opportunities that are open to the persons who live there, rather than its *physical* attributes (although some can be a very good proxy, such as the number of beds).

Unfortunately, institutional culture can be replicated quite easily in community-based services, with choice and control constrained, quality of support compromised and quality of life poor (Mansell 2010; Chow and Priebe 2013; Crowther 2019; Bigby et al 2019). Change of culture in newly-developed community services is as essential as change of physical environment (Parker 2010). For this reason, it has been argued that deinstitutionalisation should involve abolition of laws that allow 'substituted decision-making' that enable deprivation of liberty and coercive intervention.

In response to some of these barriers, some countries have introduced individualised funding systems such as various forms of self-directed support:

> Self-directed support is about people being in control of the support they need to live the life they choose. You may have heard it being referred to as 'personalisation' or 'personal budgets'. There are different ways to describe it, but whatever name's given to it - it's about giving people real power and control over their lives.
>
> (In Control 2020)

These approaches facilitate community living, expand choice and control, and offer greater flexibility with changing needs. For example, in England, persons with physical or sensory disabilities led the independent living movement and developed a model of community services based on provision of personal assistance. This helped change legislation for persons with disabilities to receive direct payments and have more control over their care.

Currently in England, *personal budgets* (where funding is devolved by statutory bodies to individuals) give persons with disabilities more freedom, control and choice about how to use this resource. *Direct payments* go further and allow budget holders to purchase their own care and support services. Personal budgets (and direct payments) enable users to achieve better outcomes, including feeling more in control of their lives, improved quality of life and care, access to more appropriate support, improved mental health and wellbeing, social participation and relationships, and confidence and skills (Glendinning et al 2008; Larsen et al 2015). Many individuals also report living a fuller life, feeling they are 'less of burden' on their families, and having greater control and independence. However, older persons show less clear benefit compared to younger persons (Hatton and Waters 2012; Woolham et al 2017), and some do not want the 'additional burden' of planning and managing their own support (Netten et al 2012b). Moreover, individualistic approaches to self-directed support do not necessarily address power imbalances between persons with disabilities and the public bodies that allocate the resources (Stevens et al 2011).

One consequence is that state bodies need to ensure that these new markets for care

services – whether funded by various means of self-directed support, or by individuals (especially older persons) out of their own accumulated resources – are functioning both efficiently and fairly, and not exploiting those persons who purchase services. Supporting individuals to make informed purchases is therefore another component of a deinstitutionalisation policy.

CASE STUDY P

Supporting persons with intellectual disabilities during COVID-19 in Bradford, England

The approach of the Learning Disability Services in Bradford to supporting persons with intellectual disabilities has been to base strategic decisions about services and supports on human rights principles centring on inherent dignity, choice and control over daily living. The approach has led to fewer persons living in larger congregate places, such as inpatient units, big care homes and big housing units.

Bradford has worked with user-led organisations and local NGOs to consult with persons on what they want to do with their lives. This has included asking about their views about the use of day centres and other traditional models of social care services.

The response to COVID-19 has been to stick with these principles during the pandemic, rather than revert to forms of institutionalisation. Maximising flexibility of how persons are supported, majoring on getting them connected electronically so persons can keep up and expand their connections to others, and doing a large-scale survey of persons with intellectual disabilities in the district including asking what they want during and beyond COVID-19.

The services have also utilised human rights legal principles in applying the 'presumption of necessity' as a fundamental maxim. This emphasises trust in persons and belief in their ability to know and understand what support works best during the pandemic. Personalisation tools such as Direct Payments have been used very flexibly during the pandemic to enable persons and their families to develop highly person-centred plans which reflect their best understanding of how to minimise infection control risks.

Bradford is focusing on support that minimises risk of COVID-19 infection AND supports persons to live a fulfilling life. Bradford is also learning that this approach is financially better, as community-based support is less expensive than traditional institutional models of care.

Elaine James and Rob Mitchell, Bradford Council

LACK OF POLITICAL WILL

Many countries have subscribed to international norms and ratified policies related to deinstitutionalisation, but governments often fail to implement them (Shen and Snowden 2014). Political leaders may not recognise the need for deinstitutionalisation, or they may profess to 'get it' but lack the political will to initiate a reform process (see Case study Q).

Some years ago, a survey – led by WHO officials – was conducted of 'international mental health experts and leaders' to identify barriers to service development in LMICs. Although specific to psychosocial disabilities, the lessons drawn from the survey have wider pertinence.

First, many of the barriers to progress in development of mental health services can be overcome by generation of sufficient political will to improve availability of and access to humane mental health care.

> The words 'politics' and 'political' were repeated 145 times in the answers of the 57 respondents in our survey, without being prompted by use in the survey questions. Political will, in this context, refers to the inclination, shaped by convictions or incentives, for policymakers to take action and to make or block change. Political will is likely to be directly affected by national and international factors, such as lobbying by professionals, consumers' groups, and other advocacy groups; expressions of public opinion; and donors' political priorities.
>
> (Saraceno et al 2007, p. 1171)

These authors identified three sets of factors that shape and influence political will and policy action: the national political environment, advocacy (in this case, for persons with psychosocial disabilities), and transnational influence.

The long-term timelines to achieve progress require long-term commitments by policy-makers. However, deinstitutionalisation does not offer immediate political gains, as the benefits of closing institutions and moving to community-based services may only be apparent some years later, and beyond the usual electoral cycle. Indeed, there may simply be few votes to win from a policy of deinstitutionalisation, given the indifference or hostility shown by many members of the general public to persons with disabilities and older persons. As a result, the rhetoric is not being matched by reality and, with inadequate government accountability, the funding designated for deinstitutionalisation may be misallocated (perhaps even fraudulently in some instances) as initial interest in changing the status quo wanes.

t has been suggested that the medical, individualistic and charitable models of disability sustain legal and social regimes of segregation, isolation and discrimination, and lead to deprivations of liberty (Flynn et al 2019). This relates to the failure to recognise the strengths and needs of persons with disabilities, or their rights. In many cases, persons who may lack capacity are not viewed as deprived of liberty but 'cared for', and social care institutions (such as care homes or group homes) are not seen as 'settings in which deprivation of liberty occurs'. Only when disability-specific deprivations of liberty are recognised can the legal and other frameworks underpinning these discriminatory systems change. However, it is argued that law reforms are not sufficient and need to be complemented by a major shift in the societal perception of persons with disabilities and the political will to pursue change (Flynn et al 2019).

Another consideration is insufficient government budgets allocated to persons with disabilities and older persons in disadvantaged circumstances. In most countries, not enough resources are available for community-based alternatives to congregate living settings; however, even with resources and reforms planned for many years, achieving progress can be challenging (Parker 2010). Recently, UN Special Rapporteurs on Disability and Housing highlighted the systematic misuse of EU funds to maintain the system of institutional care – institutions being reconstructed, expanded and built – instead of supporting initiatives that enable persons with disabilities to live and participate in the community (Validity 2020). Many countries still invest more resources in institutional care than in developing community services (European Commission 2009; Parker 2010; Parker and Bulic 2016).

The reform of psychiatric care in the Czech Republic

After the collapse of communism in Czechoslovakia in 1989, care for persons with psychosocial disabilities was provided mainly by a network of outpatient psychiatrists and psychiatric hospitals. The system needed urgent reform, especially with regards to large psychiatric hospitals and other congregate care settings, establishing community services, professional training, and public education about psychosocial disabilities, stigma and discrimination (Hoschl et al 2012). Since the 1990s, there have been several initiatives to reform psychiatric care, but these efforts did not lead to significant changes of the system due to a variety of reasons, including frequent changes in the Ministry of Health and in healthcare policies, lack of funding and milestones, and inadequate support for reform in general (Hudson and Dragomirecka 2019).

In 2013, the transformation efforts led to the publication of the Strategy of Psychiatric Care Reform (MHCR 2013), and EU funding was allocated to the reform. However, a lack of political will to translate the strategy into implementation meant that only limited steps were taken towards the transformation (Pec 2019).

Furthermore, the fragmentation of the administration presented further challenges (e.g. the funds were administered by the Ministry of Labour and Social Affairs, but the reform was initiated by the Ministry of Health). Consequently, despite a 30% reduction in the number of psychiatric beds between 1990 and 2015, there were still 18 public psychiatric hospitals with 8,633 beds and 1,308 acute beds in psychiatric wards of general hospitals in 2015 (IHIS 2016).

After four years of limited progress, there was a risk that the EU funding would have to be returned. In 2017, several implementation projects had been written rapidly, as mental health professionals involved in the reforms were trying to make up for the lost time. In 2017, ten implementation projects commenced and have made major steps towards a whole system change. These include: development of multidisciplinary community mental health centres across the country; deinstitutionalisation; adopting and piloting early detection and early intervention services for persons with severe psychosocial disabilities; adopting and piloting community mental health services for specific populations (older persons, children, forensic, substance abuse); multidisciplinary education for professionals; increasing awareness about psychosocial disabilities and reducing stigmatisation; new registers for psychiatric care; and supporting evidence-based care development.

The implementation projects run until 2022, therefore sustainability of the transition is crucial. Three National Action Plans (NAPs) 2020–2030 have been developed for (using terminology used in the Plans): Mental health; Suicide prevention; and Alzheimer's and other conditions. They set out specific tasks, measurable milestones and deadlines, with allocated funding and accountability, in an attempt to ensure the continuity of the reform. The government has endorsed the NAPs and established the Government Council for Mental Health with the aim to coordinate policies for persons with psychosocial disabilities and collaboration between ministries, administrative authorities, NGOs and professional bodies.

At present, persons with severe psychosocial disabilities still remain hospitalised for excessively long periods, in hospitals where it is difficult to adhere to the rights of persons with disabilities as defined by the CRPD, which is unjustifiable from clinical, human rights or economic point of view (Winkler et al 2016b; 2018; 2020).

The recent progress of the Czech reform shows that EU funding and support can play a crucial role in deinstitutionalisation and in advancing the rights of persons with disabilities. Many challenges still remain, including the fragmented administration, silo budgeting, insufficient legislation for mental healthcare, promotion and prevention, and high levels of stigma (Pec 2019; Winkler et al 2016a). Long-term political commitment, strong leadership and professional training will be required to change the outdated and ineffective practice engrained for decades. Although the communist-era hospitals with multiple room occupancy still exist, significant progress has been achieved in the past three years, and the scene appears set for a change of the whole system of psychiatric care.

The Czech Republic may serve as an example for other countries in the region of CEE which share similar history and face similar challenges in reforming their mental healthcare.

Eva Cyhlarova, LSE

LEAPING THE BARRIERS

While the COVID-19 pandemic has had devastating impacts on the lives of many persons living in congregate settings, as well as on their families, the spotlight on care homes, long-stay hospitals and other group living arrangements highlights the wider challenges of institutions.

Deinstitutionalisation leads to better quality of life of persons with disabilities and older persons. Successful reform of congregate living requires long-term commitment to high-quality community-based services, consistent leadership, realistic timescales and active involvement of statutory agencies and other organisations. Close co-ordination, perhaps funnelled in part through joint funding and management of services provided by health, social care and other sectors, is a fundamental requisite.

But the bedrocks of deinstitutionalisation are more enlightened public attitudes to persons with disabilities and older persons, and genuine political will to transfer the power of choice and control to persons with disabilities and older persons.

5 CONCLUSIONS AND RECOMMENDATIONS

Across the world, there are millions of people living in congregate settings that deny them their human rights and fundamental freedoms. Persons with disabilities, children whose families are unable to support them, and many older persons with needs for care are accommodated in settings that are unacceptably restrictive, offer poor quality of care, and lead to very poor quality of life. In this report we have documented the situation today in relation to institutionalisation of persons with disabilities and older persons, and then looked particularly at the impact of COVID-19. We drew evidence from across the life-course and from across the world. We highlighted the many arguments for deinstitutionalisation. We also identified a range of policy and other measures that must be taken to bring about these much-needed changes in the lives of so many children, persons with disabilities and older persons.

In closing, we recommend a number of measures for governments, international agencies, service providers and civil society in order to shift the balance of support from institutional care to community-based services, and to improve the lives of persons with disabilities and older persons.

Improve societal awareness and tackle discrimination

- Address prejudice against persons with disabilities and ageism, including stigma and discrimination, through legislative and other channels.
- Commit to long-term action, given that, historically, societies have been resistant to change.

Involvement

- Involve persons with disabilities and older persons in all discussions of policy change and practice development.

Establish community-based care

- Develop high-quality community services to reduce the likelihood of institutions emerging and to ensure that closing an institution does not result in adverse consequences (such as homelessness, poor health or the use of restriction orders). Persons with disabilities living in community settings should enjoy a quality of life equivalent to that enjoyed by the rest of the population.
- Support persons with disabilities and older persons to make informed choices about where they live, and with whom. Support them to participate as fully as they wish in the everyday life of their community.

  Support persons with disabilities and older persons to make informed choices about how they engage with health, care and other services. Increase their control over decisions that affect their lives. Ensure flexibility in health, social care and other systems as individual needs, circumstances and preferences change.
- Ensure that institutional culture is not replicated in community-based services through, for example, restrictions on choice, independence and control. This must be the aim whether community services are provided by public, third sector or private sector organisations.
- Assist families to help them support the best quality of life for persons with disabilities. Reduce the immediate and longer-term adverse consequences of being a family carer.

- Ensure that every child, whatever their disabilities or needs, lives in a family setting.
- Ensure that older persons have the freedom to choose where they live (including through advance directives as necessary) and are not forced into a particular arrangement or place of living. Address human rights violations in any and every setting.

Commit adequate funding

- Recognise the rights and needs of persons with disabilities and older persons by committing sufficient funding to community-based support.
- Recognise that a high-quality community-based system of support for persons with disabilities and older persons may cost more than institutional care. Make a long-term commitment to protect the necessary additional resources.
- Transfer resources from institutions to community-based services. Plan for double running costs in the short-term until all resources currently tied up in institutions can be released. Ring-fence those transferred resources.
- Support countries to create systems that overcome the challenge of financing community-based services and supports from multiple budgets. Ensure that new inter-agency arrangements are cemented in place for the long-term.
- Create new employment opportunities for persons with disabilities as a key part of national strategies and local plans for closing institutions.
- Ensure that international funding supports initiatives that enable persons with disabilities to live and participate in the community, rather than reinforcing institutional structures.

Improve legal and policy frameworks

- Ensure that legal and policy frameworks incentivise community-based support and discourage the placement of persons with disabilities in institutions.
- Create incentives for health systems to finance and deliver high-quality care and support in the community rather than in institutions.
- Amend laws that allow 'substituted decision-making' that enable deprivation of liberty and coercive intervention.

Responding to pandemics and other emergencies

- Commit adequate resources to health and care systems to protect persons with disabilities and older persons, including conditions of employment for staff, training in infection control, and provision of PPE and other resources.
- Ensure lessons are learnt from evidence suggesting that infection prevention and control is particularly difficult in larger and more crowded congregate settings. Regulate so that new facilities are designed on non-traditional models and that existing settings are remodelled.
- Ensure that residents in congregate care settings and their families participate in decisions on measures that may constrain their freedoms over and above those restrictions considered necessary for the general population.

Commit to long-term action

- Recognise the need – through policy reform if necessary – for long-term financial commitment, service planning and monitoring to achieve successful deinstitutionalisation and better quality of life of persons with disabilities and older persons.

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