Nature and organisation of Institutions for persons with disabilities in Portugal

FINAL REPORT

FEBRUARY 2022

This publication was produced for review by the Directorate-General Regional and Urban Policy (DG REGIO). It was prepared by Alexandra Lopes, AMI Expert Nº 2019-0397, under Contract No 2020CE160AT072.

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List of Acronyms

ADLs	Activities of Daily Living
CACI	Centro de Atividades e Capacitação para a Inclusão
CAO	Centro de Atividades Ocupacionais
CAVI	Centro de Apoio à Vida Independente
CFR	Charter of Fundamental Rights
CNIS	Confederação Nacional das Instituições de Solidariedade
DG REGIO	Directorate-General Regional and Urban Policy
EQUASS	European Quality in Social Services
ERDF	European Regional Development Fund
EU	European Union
ESF	European Social Funds
INR	Instituto Nacional para a Reabilitação
IP	Individual Plan
IPSS	Instituição Particular de Solidariedade Social
MAVI	Modelo de Apoio à Vida Independente
MTSSS	Ministério do Trabalho, Solidariedade e Segurança Social
NGO	Nongovernmental Organisation
ODDH	Observatório da Deficiência e dos Direitos Humanos
PARES	Programa para o Alargamento da Rede de Equipamentos Sociais
PO	Personal Ombudsman
RNCCI	Rede Nacional de Cuidados Continuados Integrados
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Executive Summary

Introduction and structure of the report

Emphasis on the implications of Article 19 of the United Nations Convention on Rights of Persons with Disabilities (CRPD) – *Persons with disabilities have the right to living independently and being included in the community* – has led to a growing recognition that services provided in residential care facilities segregated from the community are somehow at odds with the Convention and with the principles and rights it defines. And although the CRPD does not make any explicit reference to closing institutions, it paves the way for deinstitutionalisation as the preferential route for the development of assistance and support services to persons with disabilities. This has translated into a growing visibility of the topic of deinstitutionalisation in the policy agenda of the European Union. The policy goals set in the Union for Equality – Strategy for the Rights of Persons with Disabilities 2021-2030 are clear in the vision of guaranteeing that persons with disabilities can effectively exercise their right to live independently and be included in the community, with choices equal to those of others about their place of residence and with whom and how they live. In that same policy document, the European Commission (EC) states its commitment with supporting national, regional, and local authorities of Member States in their efforts for deinstitutionalisation and independent living.

In the light of this, the EC has been negotiating with Portugal the implementation of policies that foster community-care of persons with disabilities in view of avoiding institutionalisation and promoting deinstitutionalisation of those currently living in institutional care. The process, however, is unlikely to take place in the short-term, especially because in Portugal there is a very clear underdevelopment of community-based services. In fact, and looking at the process of policy development, to increase the chances of a successful transition for all those currently institutionalised, it is going to be necessary to implement some transitional measures.

It was with this broad goal in mind that the expert has drafted this report. It contains a critical examination of how institutions providing residential care are operating in Portugal and to what extent they align their practices with the principles of the UNCRPD and with general dispositions on matters of fundamental human rights and freedoms.

The report sets out the findings of the analysis commissioned by Directorate-General Regional and Urban Policy (DG REGIO) on the nature and organisation of services in institutions for persons with disabilities supported by the European Regional Development Fund (ERDF) in Portugal. In this report, the expert looks at how residential care is organised in Portugal and at how the delivery of services is being done in a sample of institutions in view of: (1) identifying gaps and deficiencies that may create obstacles to the realisation of the principles set out in the UNCRPD; (2) identifying promising practices that can ensure the enjoyment of human rights and the accomplishment of the goal of inclusion in the community. The report also includes recommendations on concrete actions needed to improve the organisation and operations of residential care facilities in view of supporting them in their path towards a rights-based approach in service delivery that puts the person, his/her needs, preferences, choices, and decisions at the centre with a specific eye on aspects that need to be tackled to pave the way for transition to community-based support. The report merges work carried out under Contract No 2019CE16BAT159 with work carried out under Task 1 of Contract No 2020CE160AT072.

Conceptual and methodological framework

The analysis of how residential care services for persons with disabilities are organised and delivered in a sample of institutions in Portugal was guided by the consideration of to what extent they concur to the realisation of the rights enshrined in the UNCRPD and under the framework of the CFR. The starting assumption is that living arrangements have a fundamental role to play in the realisation, not only of aspects of rights more obviously associated with space and the environment where one lives, but also of other aspects of rights such as equality, non-discrimination, autonomy, freedom of movement, legal capacity, to mention a few. The dimensions of analysis that were considered directly stem from the principles listed in the CFR and in the CRPD.

The analysis was further influenced by the wealth of literature that has been published over the years on factors that can improve the quality of life of residents in institutional care. One approach that was more central in the analysis concerns the implementation of person-centred models of service provision. In this report, person-centred service provision is about planning for service delivery considering what the person with disabilities wants and prefers. It is about a positive focus on what support is needed for the person to do what he/she wants to do rather than what he/she cannot do. Person-centred service provision is about having control of one's life and deciding on aspects of daily life. It is about being an active agent of one's life project and not a passive recipient of the actions of others. Person-centred service provision is, as the expert defines it, about delivering services putting the fundamental rights and freedoms of serviced clients at the centre.

The contents of the report are supported by evidence that was collected during fieldwork visits to a sample of institutions that operate in Portugal and deliver residential care services to persons with disabilities. Fieldwork has involved observation of sites and interviews with managers, staff, residents, and relatives of residents. Documental analysis of regulations, protocols, websites, and other documental sources collected from the institutions' representatives and/or available for public consultation was also part of the methodological approach. Evidence collected from fieldwork visits includes visits to a total of 11 institutions. Some were visited in 2020, under Contract No 2019CE16BAT159 (a total of 7), while others were visited in 2021 under Contract No 2020CE160AT072 (a total of 4). The selection of institutions was done from a list of eligible cases provided by DG-REGIO and tried to secure variety of institutions considering size, location and type of services that are delivered. The selection did not follow any random sampling method of extraction and was done following a purposive sampling approach.

Organisation and delivery of residential care

The evidence collected from the fieldwork visits to institutions was analysed in the light of a rights-based analytical framework. Conclusions are introduced as general and examples from the sampled institutions are pinpointed for their value as illustrations of the arguments put forward. Findings are organised under headings that mirror the dimensions of analysis that were considered. They are used to offer a systematic analysis of the evidence collected more than to suggest that there are clear boundaries between the issues addressed under each heading.

In regard to the living conditions in institutions, there are two opposing trends in institutions, although not necessarily translating into such clear cuts in terms of the model of care they promote and in terms of the impacts they have on the lives of residents if analysed from a rights-based approach. On the one side, there are institutions that keep struggling to overcome the limitations of worn-out ill-adapted spaces that offer sub-standard conditions to residents. These are institutions that are focused almost exclusively on securing a path of modernisation of facilities, which they believe will solve all problems and align the service provider with the framework of rights of persons with disabilities. On the other hand, there are institutions that have engaged in significant efforts to modernise their facilities, proudly presenting them as a relevant step forward in securing the best care for their residents. Some of these institutions, however, show how misleading the path of modernisation may be as new and modern spaces too often fall short in embracing principles of inclusive design, of promotion of autonomy and respect for privacy, and inclusion in the community.

Visits to sampled institutions have shown that the way operations are run coupled with a culture of care still anchored in disempowering understandings of disability leaves very little room for residents to exercise choice and be autonomous. Block treatment combined with a very rigid segmentation of time to perform sequences of tasks limits personal autonomy and choice. The effects of the procedural aspects are amplified by the resilience of some cultural understandings about disability and more specifically about the capacity (or lack of it) of persons with disabilities to exercise choice, which ends up legitimising the *status quo* of procedural aspects.

The social space of visited institutions tends to be a closed space, with meaningful relationships of residents involving almost exclusively other residents or, at best, users of other services offered by the institution. Opportunities to interact with people outside the institution are scarce. Relatives of residents do not engage in regular interactions with the institutions beyond the moments of administrative encounter defined in the regulations for the sector. Families will typically go to institutions to pick their relatives and bring them to their homes for some days. Participation in activities of daily living of residents at the institution was not allowed in all but one of the visited institutions.

What prevails in the visited institutions is a model of care rather than a model of support. Although all service providers work with individual plans of development, they do not seem to go beyond the bureaucracy of its elaboration. Block treatment is the norm and activities are organised for the group, with little room to accommodate individual-specific needs and requests. Services are designed to meet the basic needs of residents and only rarely integrate broader aspects of the development of competences and skills. In terms of access to health care services, residents in visited institutions benefit from national provisions in healthcare but adaptation to the specific needs of some individuals is rarely met. This is particularly the case with residents that couple disability with mental health problems, a situation that is challenging both for individuals and institutions.

Participation in the community tends to translate into organised forms of participation moderated by the staff, with a relatively narrow scope of activities being allowed and most of the times following the same principles of organisation of block treatment approaches. In practice, this translates into a series of outside activities and field trips to the community that are meant to break up with the routine of service provision: occasional visits to public amenities, trips to shops and walks outside in the city. CAOs – Centres for Occupational Activities (meanwhile rebranded as CACIs) are the only equivalent to an experience of work but tend to offer a limited menu of occupational activities that many residents find boring and that are not necessarily aligned with any project of autonomisation.

Regarding legal capacity, what the expert found was a resilient model of care that assumes that people with disabilities, especially those with intellectual disabilities and developmental disorders, are not capable of making good decisions and therefore need to follow decisions made by others “in their best interest”. This explains the scenario found in visited institutions, one of limited recognition of the right of persons with disabilities to participate in all decisions concerning their lives and their interests. Despite the unprecedented recognition of the rights of people with disabilities in our times, visits to the sampled institutions have unravelled some important limitations in the opportunities residents have to exercise full-fledged citizenship rights, with an emphasis on lack of access to information; lack of access to means of communication; persisting physical barriers to the participation of residents as citizens in the community. Complaints and investigations are dominated by bureaucratic protocols, most of them imposed by the regulator. There are no mechanisms for residents to raise questions and complaints besides talking with the staff or the director of the care facility. There is no access of residents to any independent body outside the institution. Access to the Ombudsperson services dedicated to persons with disabilities must be done by phone or email, both of which are not available for many of the residents in the visited institutions. Decisions concerning admission to institutions do not always involve a transparent process, as they are almost fully controlled by the institutions. Criteria for admission include assessment of needs and fit of the candidate to the services offered by the institution. Cases of social need motivated by socioeconomic deprivation are given priority in admission. Formal leaving rules are included in the institutions' norms to account for the situations where the resident does not adapt to the facilities and the service contract must be terminated. There is nothing formally defined about aftercare. Deinstitutionalisation and aftercare seem to be strangers at present for the visited institutions.

In almost all visited institutions spaces are primarily organised to promote communal life with no room for the individual pursuit of interests or activities, alone or in smaller groups of individuals. It is difficult to find opportunities to be with others in private, namely with visitors, to have conversations of a private and/or confidential nature. Individual dignity is often hurt due to a combination of factors. Shortage of staff pressures towards block treatment and the search for optimisation in daily operations rushes caregiving activities in ways that often forget the intimate nature of some aspects of caregiving and hurt the right of individuals to privacy.

Shortage of staff also leads to a perceived excessive workload, which combined with the low salaries, are the cause for the narrative of discontent heard from almost all interviewed staff members. This is exacerbated among caregivers, a group severely impacted by high rotation of staff and high levels of absenteeism. Altogether, these deteriorate the working conditions and are likely to impact negatively on the care provided to residents. Recruitment is severely constrained by the shortage of interested applicants. This is used as an explanation for the absence of strict recruitment criteria. Training opportunities are limited and tend to focus exclusively on techniques to execute tasks. Relationships between staff with coordination roles and caregivers are overly verticalised and caregivers tend to be considered lower-level workers. This accounts for the tensions among staff observed in many of the visited institutions.

Challenges and opportunities in residential care for persons with disabilities

Considering the evidence collected during fieldwork visits, the report offers a total of 70 recommendations for and about institutions providing residential care services for persons with disabilities. The recommendations address aspects of organisation and delivery of services in institutional care settings that are considered of high relevance from a rights-based perspective. The guiding principle for the formulation of recommendations was to introduce the changes and adaptations necessary to improve the living conditions of residents, safeguarding their fundamental rights and freedoms, and promoting environments where individuals can live a complete and fulfilling life while paving the way for transitional arrangements that can facilitate the development of deinstitutionalisation projects and/or alternative modes of living in the community.

The 70 recommendations are grouped under 7 dimensions of valuation that address broad domains of how institutions are organised and deliver their services. To keep the recommendations organised in a clear manner and easy to read, a simplified logic is used in addressing the individual actors. Some recommendations are directed at the service providers and their sectoral representatives, others at national and local authorities, others at the European Commission and its agencies. Recommendations are discussed in terms of their feasibility in the short, mid, and long term as well as in terms of their potential impact in facilitating deinstitutionalisation.

The first group of recommendations is oriented towards the promotion of a good quality of life of residents and emphasises primarily the need to move towards a person-centred model of service provision. It includes a series of actions that are required to implement the needed changes in cultures of care, creating environments where residents can be in control of what constitutes the aspects of their lives and have their preferences, wishes and expectations placed at the centre of the service provision. Among the actions highlighted by the expert, training of staff ranks very high in the list of priorities.

The second group of recommendations is oriented precisely to issues related to staff as staff is a key component of the service delivery and has a major impact on how residents live their daily life and on the quality of that life. This dimension takes us to a challenging domain as there are many different moving parts that account for the working environment found in the visited institutions. The most pressing issue, however, seems to concern one specific group of workers: caregivers. The recommendations offered are primarily targeting this group. They include actions to improve recruitment, training, and retention of staff, but also issues related to regulations in place concerning staff ratios in view of moving to more flexible arrangements based on needs of residents.

The third group of recommendations focuses on safeguarding and protecting residents while empowering them to be in charge of their lives. The expert addresses the need to move from a charitable view of disability, that tends to see persons with disabilities as frail and requiring protection by others, to an empowering approach that takes all aspects of life, including risks, as aspects of training for autonomy and more independent living. Recommendations also address the need to work with individuals so that they are aware of their rights and of how they can safeguard their rights, including access to information and to independent agencies.

The fourth group of recommendations concerns improving approaches to personal development and healthcare. On one hand, the expert considers that personal development should be approached from the angle of what the person with disabilities wants to do with his/her life and not from the angle of what he/she can do. Personal development plans must be organised to contain a long-term vision about the life project of the person and about what would it take for that vision to be achieved, namely in view of deinstitutionalisation. On the other hand, and while building this long-term vision, the expert considers that personal development must be addressed from a holistic perspective. Personal development cannot be confined to dimensions of satisfaction of basic needs of daily life. It must also include a project of life with space for consideration of what is enshrined in the Pillar of Social Rights as participation in society: access to education, training, work and employment, and other dimensions of social life such as culture, leisure, and sports. Finally, and because enjoying a good quality of life is also about living healthy and having access to healthcare, the expert offers recommendations to facilitate access of residents to all domains of healthcare, with a specific focus on mental healthcare.

In the fifth group, the expert offers recommendations to mainstream citizenship rights in service delivery. Issues addressed in this group are many: access to information in formats that are accessible to all; securing effective channels of communication that guarantee information reaches all residents; promoting awareness and proactiveness about civil and political rights; addressing with a firm hand the potential for conflict of interests that characterise existing arrangements in assessment and aid to decision-making; improving protocols of inspection on the regulator’s side, that need to be more transparent and participatory.

The sixth group of recommendations focuses on physical environments and looks at aspects related to spaces. Space has a big impact on the quality of life of those who use it and, as an overarching guideline, it should be adapted to meet their needs. Aspects addressed include how space is designed, where residences are located, and how health and safety issues are addressed. Residential care facilities should feel homely and be accessible while promoting the privacy, dignity, and autonomy of their residents. It is recommended that national authorities revise rules to award funding and include more strict assessments of projects considering aspects such as the following: inclusion of assistive technologies; creation of spaces for private use; preferential offer of individual bedrooms; private access to bathrooms; possibilities of personalisation of space; availability of personal and secure storage spaces; diversification of spaces; safe access to outdoor spaces; facilitation of autonomy and privacy in all aspects of daily life.

The seventh and last group of recommendations concerns a more systemic reading of institutional care dynamics. The expert is fully convinced that the root cause of many of the problems she has observed in visited institutions is related to the model of social care provision in Portugal, especially in what concerns models of management and governance. Under this group of recommendations, the expert focus on the macro-level, beyond the single cases, and offers recommendations that are targeting primarily national authorities, the ones that have the responsibility for regulating the sector. They include dispositions on the implementation of an effective and consequential quality assessment system; and the definition of the exact place of institutional care in the social care services sector to tackle the needs of persons with disabilities, since currently institutions have no incentives to find alternative arrangements for their clients in institutional care, quite the opposite.

In summary, the report provides background material for the Commission services and offers evidence to illustrate the nature of the challenges institutions currently face if they are to align their practices with a model of service delivery based on rights and person-centred principles. The recommendations put forward were formulated to assist them in that path. Some are easier to achieve than others and careful planning of interventions may be required to tackle some aspects of change. Establishing priorities is something the expert avoids when the subject in consideration involves human rights. It would be hard to argue that some rights are more important than others. What the expert knows is that human rights tend to have a spill-over effect: the realisation of some tends to facilitate the realisation of others. From that perspective, the magnitude of the changes will most likely be amplified when service providers and other relevant stakeholders start the process, with the combination of recommended actions likely to have impacts that are bigger than the simple sum of each one’s unique effects.

What the expert also firmly believes is that deinstitutionalisation policies in Portugal will somehow have to involve institutions. Deinstitutionalisation is not just about shutting down institutions. Shutting down institutions is, at best, the long-term vision. The way to get there involves developing individual life projects, by and with individuals concerned, to create the conditions for a successful transition to life in the community in a way that guarantees that fundamental rights and freedoms are safeguarded in all steps taken. And this will have to start inside institutions while the person is still a resident. In that sense, taking them out of the equation when discussing disability policies may be a critical mistake. In her report, the expert tries to shed some light on how some changes can be triggered intervening at the level of institutions and in view of moving forward the agenda of deinstitutionalisation. That is the goal of the recommendations put forward.

Nature and Organisation of Institutions for Persons with Disabilities in Portugal

FINAL REPORT

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Introduction: Purpose and Scope

Emphasis on the implications of Article 19[1] of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) – *Persons with disabilities have the right to living independently and being included in the community* – has led to a growing recognition that services provided in residential care facilities segregated from the community are somehow at odds with the Convention and with the principles and rights it defines. And although the UNCRPD does not make any explicit reference to closing institutions, it paves the way for deinstitutionalisation as the preferential route for the development of assistance and support services to persons with disabilities, which has translated into a growing visibility of the topic of deinstitutionalisation in the policy agenda of the European Union. The policy goals set in the Union for Equality – Strategy for the Rights of Persons with Disabilities 2021-2030 are clear in the vision of guaranteeing that persons with disabilities can effectively exercise their right to live independently and be included in the community, with choices equal to those of others about their place of residence and with whom and how they live. In that same policy document, the European Commission (EC) states its commitment with supporting national, regional, and local authorities of Member States in their efforts for deinstitutionalisation and independent living.

Full transition to community-care however is unlikely to take place in the short-term, especially in a country such as Portugal where there is a very clear underdevelopment of community-based services. On the other hand, and to increase the chances of a successful transition for all those currently institutionalised, it is likely to require some transitional measures.

In the light of this, and because institutions providing residential care are not only likely to continue to exist for quite some time but will be an active party in the process of deinstitutionalisation itself, it is of critical importance they align their practices with the principles of the UNCRPD and with general dispositions on matters of fundamental human rights and freedoms. It is also important that national policies and dispositions on disability services are aligned with the goal of deinstitutionalisation, creating the needed support systems and transitional measures that will secure a successful transition of those in institutional care to other living arrangements that promote full inclusion and participation in the community.

This report, based on research work carried out on a sample of Portuguese (PT) institutions providing institutional care for persons with disabilities that have received European Regional Development Fund (ERDF) funding, discusses gaps and deficiencies in how institutional care facilities are organised and deliver their services, in Portugal, that may put at risk some fundamental rights of persons with disabilities, with an emphasis on autonomy, freedom of choice, privacy, dignity and citizenship. The report further offers some recommendations on paths of action that can be activated to overcome these risks and pave the way for a successful implementation of deinstitutionalisation policies.

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[1]

Article 19 (UNCRPD)

Living independently and being included in the community

States Parties to the present Convention recognise 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.

The main objective of this report is to provide background material for the Commission services to assess whether the living conditions in a sample of Portuguese institutions supported by the ERDF comply with the Charter of Fundamental Rights (CFR) and with the UNCRPD. The report is expected to also provide recommendations on how to improve in the short term the functioning of the institutions in the light of fundamental rights, human rights, and fundamental freedoms, with a specific eye on aspects that need to be tackled to pave the way for transition to community-based support.

The report is organised into three sections. Section 1 outlines the conceptual and methodological framework of the work carried out. Section 2 offers the conclusions of the fieldwork the expert has done concerning the visited institutions. Section 3 outlines the main recommendations offered by the expert.

Section 1. Conceptual and Methodological Framework

Conceptual framework: a rights-based approach

The analysis of how residential care services for persons with disabilities are organised and delivered in a sample of institutions in Portugal was guided by the consideration of to what extent they concur to the realisation of the rights enshrined in the UNCRPD and under the framework of the CFR. The starting assumption is that living arrangements do have a fundamental role to play in the realisation, not only of aspects of rights more obviously associated with space and the environment where one lives, but also of other aspects of rights such as equality, non-discrimination, autonomy, freedom of movement, legal capacity, to mention a few.

Considering the characteristics of institutional care settings, the goal of the report was to analyse to what extent residents can realise some of their fundamental rights, namely:

- The right to an adequate standard of living and to fully accessible environments
- The right to respect for personal autonomy, family life and citizenship
- The right to provision of adequate healthcare
- The right to equal recognition before the law
- The right to be safe, without suffering degrading treatment or punishment
- The right to freedom of expression and opinion, as well as to access to information
- The right to respect for privacy and dignity
- The right to education, habilitation, and rehabilitation, to work and employment
- The right to participation in community life in all its dimensions
- The right to freedom of movement and personal mobility.

Following this list, the analysis of how each of the visited institutions operates and delivers residential care services was carried out following a protocol that considers dimensions of analysis directly stemming from the principles listed in the CFR and in the UNCRPD. The dimensions analysed and used for the discussion of findings presented in section 2 of this report are the following:

1. Living conditions (location, accessibility, characteristics of facilities)
2. Personal autonomy and choice
3. Family life
4. Citizenship
5. Provision of health care
6. Participation in the community (employment, education, leisure, and cultural life)
7. Legal capacity of residents
8. Confidentiality and privacy
9. Personnel (hiring protocols, training opportunities, support mechanisms)
10. Restraint and seclusion
11. Complaints and investigations
12. Admission and leaving rules / aftercare.

The analysis was further influenced by the wealth of literature that has been published over the years on factors that can improve the quality of life of residents in institutional care. One approach that was more central in the analysis concerns the implementation of person-centred models of service provision. The meaning of the term person-centred care remains elusive as it is often put forward by authors without a clear definition of what they mean by it. It is a term that is associated in its origins with the work of disability activists and disability movements who have claimed a shift in the balance of power between the persons with disabilities and the services they rely on (Lewis and Sanderson, 2011)[2]. In this report, person-centred service provision is about planning for service delivery considering what the person with disabilities wants and prefers. It is about a positive focus on what support is needed for the person to do what he/she wants to do rather than what he/she cannot do. Person-centred service provision is about having control of one's life and deciding on aspects of daily life. It is about being an active agent of one's life project and not a passive recipient of the actions of others. Person-centred service provision is, as the expert defines it, about delivering services putting the fundamental rights and freedoms of serviced clients at the centre. This is the approach used in this report.

Methodological framework

The contents of this report are supported by evidence that was collected using two complementary protocols:

i) Fieldwork visits to a sample of institutions that operate in Portugal and deliver residential care services to persons with disabilities, involving observation of sites and interviews with managers, staff, residents, and relatives of residents.
ii) Documental analysis of regulations, protocols, websites, and other documental sources collected from the institutions' representatives and/or available for public consultation.

Evidence collected from fieldwork visits includes visits to a total of 11 institutions. Some were visited in 2020, under Contract No 2019CE16BAT159 (a total of 7), while others were visited in 2021 under Contract No 2020CE160AT072 (a total of 4). The selection of institutions was done from a list of eligible cases provided by DG-REGIO and tried to secure variety of institutions considering size, location and type of services that are delivered. The selection did not follow any random sampling method of extraction and was done following a purposive sampling approach.

The fieldwork methodology was agreed with DG-REGIO. Institutions were visited during the months of August and September 2020 and the same months in 2021. In the context of the Sars-Cov-2 pandemic and to minimise risks to all those involved, while managing restrictions on visitations imposed by national regulations, summer months were the period when institutions felt more comfortable to host the expert. Each visit was planned with the management of each organisation to guarantee the completion of all tasks included in the methodological plan. The same plan of work, with minor adjustments, was used for the visits to all the selected institutions. Visits were prepared in advance following phone contacts and formal emails where the purpose of the visit was explained and where the logistics of the fieldwork were agreed upon. Each institution received a final plan for the organisation of the 2-day visit, where the agenda for the meetings was defined and where instructions about the selection criteria of people to be interviewed were laid out. Interviewed people included the board members of the institution, the director of the residential care facility, technical staff, caregivers, residents, and relatives of residents. During the visits, and to complement the requirements for the documental analysis concerning the organisation and operations of the institutions, documents that were not publicly available were requested by the expert to the management of the institution.

Interviews followed the ethics protocol agreed with the EC and informed consent was secured from all participants. The expert is in possession of all signed consents which are stored in a safe location only accessible to the expert. Consents can be exhibited to the EC upon request. All interviews were recorded, and files are

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[2] Lewis, J., & Sanderson, H. (2011). *A practical guide to delivering personalisation: person-centred practice in health and social care*. Jessica Kingsley Publishers.

encrypted and stored in the expert's personal computer, with access by password. Recordings were deleted from the recording device. In total, the expert has interviewed 195 individuals.

The expert has used two techniques of interviewing. Individual interviews were used for the directors of organisations and the directors of the residential care units. Relatives of residents were also individually interviewed. Technical staff, care staff, and residents were interviewed mostly in groups. After the first visit, where all interviews were done individually, the expert was convinced that being individually in a room with the expert for the staff and residents was uncomfortable and individuals were very careful and self-conscious about their answers. In the second visit, the expert applied the group interview technique to these specific groups and the results were much better. Group interview offers the comfort of the peers and makes individuals more relaxed to share some information. Considering the interviews were not so much focused on personal elements of individual lives but rather on the way the organisations operate and deliver care, the trade-off was considered pending to the group interview technique.

During the visits to the organisations, the expert has also followed a standardised protocol of direct observation. An observation grid was used to record in a systematic manner features of the spaces visited, as agreed with DG-REGIO. A summary table of classification of spaces was produced based on the indicators included in the observation grid.

The checklist of topics addressed with the different groups of interviewees followed the dimensions of analysis that framed the report.

Interviews with board of institutions

1. History of the organisation and philosophy of intervention in disability
2. Model of management and governance
3. Relationship with national authorities that regulate the sector
4. Perspectives on rights of persons with disabilities
5. Future projects

Interviews with directors of residential care facilities

1. Living conditions in the facilities
2. How autonomy and freedom of choice are perceived and addressed
3. Family life of residents
4. Healthcare
5. Participation in the community
6. Legal capacity of residents
7. Confidentiality and privacy
8. Human resources management
9. Understandings of restraint and seclusion
10. Protocols to deal with complaints and investigations
11. Admission and leaving rules

Interviews with staff with coordination responsibilities at the residential care facilities

1. Views on how the activities in the institution promote the rights of residents
2. Experiences of work inside the institution with other members of the staff
3. Identification of tensions in the services offered by the institution
4. Views on residents and their needs
5. Views on relatives of residents
6. Views on the board of the organisation

Interviews with caregivers working at the residential care facilities

1. Experiences of admission as a worker and of working at the institution
2. Views on working conditions
3. Views on living conditions of residents
4. Experiences of interaction with residents
5. Experiences of interaction with coordinating staff
6. Experiences of interaction with relatives of residents
7. Description of activities in a normal day
8. Opportunities of training
9. Understandings of disability

Interviews with residents of the residential care facilities

1. Narrative of admission in the institution
2. Evaluation of life at the institution in general
3. Experiences of interaction with other residents and with staff
4. Episodes of daily life
5. Projects and wishes for the future
6. Relationship with families and other people outside the institution
7. Complaints

Interviews with relatives of residents in the residential care facilities

1. Narrative of admission in the institution
2. Evaluation of life at the institution in general
3. Experiences of interaction with staff
4. Episodes of daily life
5. Projects and wishes for the future
6. Relationship with the resident
7. Complaints

Table 1 in the next page summarises some fundamental aspects of the methodological protocol, namely concerning the composition of the final sample.

Table 1. Main elements of the fieldwork visits protocol

	Fieldwork visits in 2020							Fieldwork visits in 2021				
Date of visit	7/8 Aug.	11/12 Aug.	21 Aug.	27/28 Aug.	3/4 Sep.	17/18 Sep.	27/28 Sep.	9/10 Aug.	14/15 Sep.	15/17 Sep.	20/21 Sep.	TOTAL
Location (NUTs II)	North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North	
Facilities included in the visit*	A+B+E	A+B	A+B	A+B	A+B	A+B	A+B	A+B	A+B	A+C+D	B	
Total number of interviews	20	19	11	15	5	18	20	25	19	24	18	194
Top management	3	2	2	1	1	3	1	3	2	3	3	24
Director of residential units	1	1	1	1	1	1	1	2	1	1	1	12
Technical staff	3	0	2	0	1	3	4	2	4	3	3	25
Caregivers staff	3	3	2	4	1	3	3	6	4	4	3	36
Residents	7	12	2	6	0	6	6	8	6	9	5	67
Relatives of residents	3	1	2	3	1	2	5	4	2	4	3	30
Souces for documental analysis												
Statutory documents	✓	✓	✓	✗	✓	✓	✓	✓	✗	✗	✓	
Internal regulation of residential home	✗	✗	✓	✗	✓	✓	✓	✓	✗	✗	✓	
Admission rules	✗	✗	✓	✗	✓	✓	✓	✓	✗	✗	✓	
Rights and duties of residents	✓	✗	✓	✗	✓	✓	✓	✗	✗	✗	✓	
Website / Social media	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	

* Legend for the typology of facilities visited by the expert

A – CAO (Centre for Occupational Activities)

B – Residential care unit

C – Nursing home for older persons

D – Healthcare unit

E – Autonomous houses

Section 2. Organisation and delivery of residential care for persons with disabilities: a rights-based approach to a sample of Portuguese institutions

In this section of the report the expert discusses the evidence collected from the fieldwork visits to institutions in the light of a rights-based analytical framework. Conclusions are introduced as general and examples from the sampled institutions are pinpointed for their value as illustrations of the arguments put forward. Excerpts from interviews are also introduced when relevant but identity of interviewees is not disclosed. The section is organised under headings that mirror the twelve dimensions of analysis introduced in section 1. They are used to offer a systematic analysis of the evidence collected more than to suggest that there are clear boundaries between the issues addressed under each heading.

The analysis offered in this section of the report is primarily based on the wealth of evidence collected from the fieldwork visits. It combines detailed analysis of recorded interviews with materials proceeding from observation of spaces and from documental analysis.

The tables presented below in the next pages summarise some of the data collected by the expert. Table 2 offers a summary of the data concerning the capacity and usage of institutions, basic demographics of users and composition of staff by gender and professional category. It was not possible to collect data about types of disabilities of residents as that information is only available in personal records and is therefore not accessible to the expert. Classification of residents according to level of dependency, as shown in table 2, reflects the classification of the technical staff of the institution of each resident according to level of support required to perform activities of daily living, including personal care activities.

The visited institutions have the legal status of IPSS – Private Institution of Social Solidarity (*Instituição Particular de Solidariedade Social*). The only exception is the one from Madeira, since in the island social care services to persons with disabilities are directly provided by the local government as part of the public network of social care. For all others, and following the national model in place, private non-profits secure provision of services that are paid by the State at a fixed rate per user. Institutions are licensed by the Social Security Institute to operate and are regularly inspected for compliance with regulatory rules and dispositions. Payments are agreed in annual negotiations between State representatives and sectoral bodies representing the providers. Services provided also involve payments from the user's pocket, calculated according to means-testing and pooling the cash benefit most individuals will get from the State due to their disability.

In the area of residential care services for persons with disabilities, and at the time this report was produced, the Portuguese system included two types of services: institutional care (*Lar Residencial*) and autonomous residences (*Residências Autónomas*). This report has focused on the first. However, in some of the visited institutions there were also adjacent autonomous residences which the expert has visited whenever allowed by the institution's representatives. Visited institutions were also managing CAOs – Centres for Occupational Activities which the expert has also visited whenever possible. CAOs operate as day centres that offer occupational activities to persons with disabilities that are not integrated in the labour market. The delivery of services in the residential care facilities (institutional care and autonomous residences alike) follows rules set by the regulator. The most recent version was published in March 2015 and is since then in place[3]

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[3] *Portaria nº59/2015*, issued by the MSSST and published on the 2nd of March 2015 defines the rules of operations of service providers offering institutional care and autonomous residences to persons with disabilities. Available at https://dre.pt/home/-/dre/66639520/details/.

Table 2. Indicators of users and staff of the visited institutions

	Fieldwork visits in 2020							Fieldwork visits in 2021			
Location (NUTs II)	North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North
Capacity and usage											
Number of places in the residence	40	16	16	51	12	24	40	77	15	40	36
Number of residents at the time of the visit	33	13	16	24	6	25	38	77	15	40	33
Places with cooperation contracts	35	16	16	(*)	12	24	38	77	14	38	32
Places to offer in the private sector	0	0	0	0	0	0	0	0	1	0	4
Waiting list (number of persons)	45	7	39	5	(**)	38	55	25	42	30	75
Residents											
Total males	15	7	10	16	4	17	20	45	10	14	22
Total females	18	6	6	8	2	8	18	32	5	26	11
Under 25	4	2	2	2	0	4	2	3	0	1	0
25-45 years old	14	6	12	4	6	11	22	29	8	13	11
45-65 years old	14	4	2	11	0	10	14	39	7	24	21
Over 65	1	1	0	0	0	0	0	6	0	2	1
Levels of dependency											
Severe dependency	14	0	6	18	0	12	18	14	2	16	28
Moderate dependency	12	9	10	6	4	9	14	40	10	15	2
No dependency	7	4	0	0	2	4	6	23	3	9	3
No family support	15	7	7	9	0	6	9	46	3	14	3
Status of accompanied adult	28	7	7	16	0	16	33	75	13	37	0
Activities of residents											
In protected employment	0	0	0	0	0	0	0	0	0	0	1
In regular employment	0	0	0	0	0	1	0	0	0	0	1
Attending training for a profession	1	0	0	0	0	1	2	0	0	0	2
Attending school	0	0	0	0	0	0	0	0	0	0	1
Attending CAO daily	32	13	16	24	6	23	36	23	12	15	19
Staff											
Total staff	26	14	14	19	4	41	27	68	15	41	21
Total males in staff	7	4	2	4	0	7	4	10	0	6	9
Technical staff	4	2	2	2	2	12	4	13	3	9	3
Caregivers staff	11	9	11	16	2	15	23	26	7	14	21

(*) In Madeira institutional care is provided directly by the local government (**) The institution is operating on a temporary license and does not accept new applications

1. Living conditions

The most obvious characteristic of institutional care is the fact it is provided within a congregate living environment. Buildings for collective use are designed to meet the functional, medical, personal, social, and housing needs of individuals who have physical, mental, and/or developmental disabilities. Over the years, and especially over the last 20 years, there have been policy developments targeting the improvement of living conditions in residential care facilities, usually by means of strict legislation defining standards that the material spaces must meet for the providers of the service to be allowed to operate. Such was the case in Portugal, with important pieces of legislation passing in the last two decades establishing technical guidance and minimum standards that institutional facilities must meet.

Legislation, however, tends to be quite limited in terms of the dimensions it considers, stopping at the material aspects of the facilities and rarely, if ever, considering the broader implications of living conditions and spaces for the fulfilment of some of the fundamental rights and principles outlined in the UNCRPD. The fieldwork carried out by the expert was not so much guided by a checklist of items in view of signalling presence/absence against a set of regulations, but rather focused on identifying features of the material living conditions in the visited institutions that can create obstacles, or opportunities, for the realisation of fundamental rights of the residents.

Location

It has long been argued that institutional care segregates users and one of the features of that segregation stems directly from the location of the facilities, separated from the community and often physically distant from it. In fact, one can hardly speak about participation and integration in the community if people are kept separated and distant from it.

Among the visited institutions, only 5 of the 11 institutions can be said to show no element of spatial segregation of persons with disabilities in the sense that they are centrally located, integrated in residential neighbourhoods with availability of services in the vicinities, served by public transportation and with surrounding areas accessible for persons with reduced mobility. In 4 out of 11, the facilities are in the outskirts of the respective village, without any access by public transportation and can be classified as the classic example of full spatial segregation. This is particularly the case of the newest facilities, typically involving sizable buildings that require big plots of land. Most of the times land is either donated by the municipalities or bought by the promoter. In both cases occupying plots away from the village is more a necessity than a choice, especially if one considers the speculation on land prices in the city centres and the financial limitations organisations have in competing for land. In fact, the visited institutions that were in the city centre were all examples of facilities that have been running for a long time, some since the foundation of the umbrella organisation, and typically in older buildings. Confronted with the need to expand and move to better spaces, institutions are often forced to choose between centrality and quality of the spaces, and they end up choosing quality of spaces. This segregation of residents is further increased by the lack of appropriate public transportation in the surroundings and in some cases by the lack of adequate urban planning as well (e.g., lack of sidewalks, absence of services and commercial activities).

> ***Example 1.*** *One of the visited institutions has been approached by the local authorities of the surrounding municipalities to run residential care services in facilities that the municipalities are willing to fund. That institution always sets as a condition for involving in the projects that the residential facilities are in the city centre. The philosophy as stated by the management is that "(…) you cannot talk about participation in the community if people are not physically present in the community."*

Spatial segregation is very detrimental for the realisation of the principle of participation in the community as it poses unsurmountable obstacles to being in the community. Residents are often dependent on the transportation services secured by the institution. The institution will organise for the transportation which often comes hand in hand with a model of participation in the community that involves "visits" to selected places, with the escort of the staff, and no real participation and engagement in the life of the community. In those cases, the person with disabilities is someone that lives in a secluded place and not a member of the community and at best he/she is someone that on and off visits the community as part of an outside activity.

To this, one can add the difficulties a segregated location brings to maintaining ties with the family and other significant people. In fact, in some of the visited institutions some residents would only be able to see visitors or go home to spend some time with their families depending on the availability of the institution to organise for the transportation of both residents and relatives. Many residents are living in residential care units that are far away from their place of origin, which is challenging for many families. This is particularly the case for those that add to disability a condition of poverty. Deprived of means to overcome expensive travelling (if car or taxi are the only alternatives), families go visit their relatives less and less often, something that was described by several residents as a source of frustration and sadness.

Example 2. *One institution runs a very modern residential care facility with state-of-the-art equipment. Inside the premises there is an in-house coffee shop that replicates what one would find outside the facilities in the community. In Portugal, coffee-shops are very typical, and most people go there for a coffee at least once a day. It is an important meeting place and a pivotal element of community life in most villages and neighbourhoods. Given this institution is located in a very remote place, where it would be unsafe for residents to try and circulate outside to go to the coffee-shop, the institution provides this in-house.*

> *M. declared he has a driving-license and drives his own vehicle. He lives in the autonomous residences of one of the visited institutions and considers having his own vehicle is fundamental to feel free since he can drive anywhere and go to places of his choice. He lives with a partner, and they value very much being able to drive to the supermarket and buy what they want. Without the vehicle they would feel very isolated from the outside world because it is impossible to walk anywhere once you step outside the premises of the residential facilities.*
>
> (Male interviewee, with mild developmental disability and fully autonomous in activities of daily living. He has a job and manages his salary. He shares an autonomous residence unit with a female partner with whom he has a marital relationship. The autonomous residence is located inside the compound where the institutional care unit also operates.)

The visited institutions that run their residential care services in centrally located facilities, although often offering poorer living conditions due to the fact they use older buildings requiring rehabilitation, offer a better experience of participation and inclusion in the community to their residents. Proximity is acknowledged by the management of institutions as a critical element in the nature of the relationship both residents and the institutions have with local communities.

Spatial integration in the community however does not come without its challenges. There were instances where it was reported some resistance from some of the neighbours to having a residence for persons with disabilities close to their houses and in their neighbourhoods. If something, this only adds evidence to claims for a continuous effort to work with the community if one is to talk about inclusion and participation of persons with disabilities.

Size and type of services

The size of the facilities is a factor that has known impacts in how they operate in terms of the organisation of spaces and daily routines. There is some variation in the sample of visited institutions, with size ranging from as low as 12 to as big as 77. National regulations in place stipulate a maximum number of residents per institutional care facility, which cannot exceed 30 individuals since 2015, but for those created before that year one still finds institutions with a higher capacity. For some of the visited institutions this may mean that their installed capacity is bigger than what they are licensed to operate under cooperation agreements. Or, alternatively, institutions turn their residential unit into two formally distinct units, therefore decreasing the number of residents per unit and complying with the regulation of 2015. The observed tendency in almost all visited institutions was having them operating with a capacity close to the maximum number allowed by law.

Number of places, however, is not the only factor involved in the size of the units. Almost all the visited institutions run their residential units within a bigger operation that involves provision of other services. More specifically, almost all residences are run next to a CAO service. In fact, there are many institutions where attending the CAO is one of the pre-requisites that need to be met for an individual to be eligible for a place at the residence. The two spaces (CAO and residence) are often managed in an integrated manner which results in the occupation of sizable buildings, that serve many users every day. Number of residents together with integration of residential care in other services results in a model of organisation of residential care that promotes the institutional feel. Among the 11 visited institutions in only 1 was the residence just a residence in a residential building specifically built for that purpose. All others involve integrated solutions where residence and CAO coexist either under the same roof, in different levels of the building, or next doors.

Example 3. *One of the visited institution runs two small residential care units in the city centre resulting from the adaptation of two flats in buildings of regular residential flats. They are both run as institutional care units. One accommodates 10 individuals, the other 6. Although requiring some intervention, to comply with legislation on universal accessibility, the two flats end up offering a residential environment much closer to what one would find in a typical Portuguese home than the big and modern unit, also run by the institution, and that accommodates 24. The layout, the use of the space, the absence of any other services besides the residence, all concur for a homely feel. Although acknowledging the new residence is more modern and comfortable, all interviewed residents prefer the flats.*

With size comes the need to have standardised protocols to manage activities of daily living that generate routines in designated spaces that become the *locus* for rigid protocols – eating areas that open at eating times; sitting rooms where to go after lunch and dinner; bathing rooms to be used only at bathing time. Among the visited institutions in only two could the expert observe a less rigid institutional routine: one was an institution where the residential care unit is separated from any other service; the other is an institution that has the residential unit organised into separate fully equipped flats. These are still collective residences and as such there are still some elements of standardisation in the organisation of daily life, but at less pronounced levels than what was found in all other institutions that combine big size with coupling of residential and occupational services.

Layout and accessibility

The sampled institutions offered a good contrast of what is currently the situation in the sector of residential care services for persons with disabilities in Portugal. The vast majority was founded in the 1970s and along the years, and as the demand for more services increased, felt the need to expand to new facilities. Some were successful in securing the financial resources either to move to new facilities or to rebuild the existing ones.

Others were not as successful and find themselves operating in worn out, dated facilities that show high levels of deterioration. Among the sampled institutions visited by the expert, 4 out of 11 are operating their residential care services in new modern facilities, 2 out of 11 are in the process of renovating/building new facilities, 2 out of 11 have a mix of both new and old facilities and 2 others are operating in facilities that are showing signs of deterioration and would benefit from renovations. Among the 11 visited institution, 1 is clearly operating in a hazardous environment that puts at risk the safety and well-being of residents and requires urgent intervention.

Considering first the ones that are operating in old facilities, in a couple of them the picture found is grim and raises serious concerns. The original buildings were not designed for their current function and adaptation was not always done according to what are the current standards. The result is a very limiting layout, especially for those residents who have mobility impairments: narrow corridors and doors; insufficient space in rooms to manoeuvre wheelchairs; ill-adapted sanitary facilities that do not facilitate independent use. These poor conditions are further aggravated by the low quality of construction in some of the visited places, resulting in rooms that are too warm in summer and too cold and damp in winter. Accessibility is compromised in some of the oldest institutions, for example with access by stairs only. Limitations of old and deteriorated facilities, coupled with lack of funding to rehabilitate, generate situations that can even be elevated to the status of health hazard.

> *A. declared she has some difficulties with mobility and requires a stroller to walk. Two years ago, she had an accident in the bathroom while showering. She tripped when entering the shower area* [the expert could see an elevated step at the entrance of the shower cabin in the institution where she lives] *and suffered a serious head injury. After that accident, the management decided it was not safe for A. to walk with the stroller and to shower standing. She is forced to use a wheelchair and is bathed by the staff. This was described by A. as causing frustration and high levels of anxiety. A. is worried she will end up losing the residual walking ability she had before the accident. She describes bathing time as the worse time of the day for her. She does not feel comfortable with others seeing her naked body and is always worried that someone will enter the bathroom and see her while she is being bathed. A. does not like living in the residence and dreams of one day having her house if she can find someone to help her with what she cannot do on her own.*
>
> (Female interviewee, with mild developmental disability and severely reduced mobility, who lives in the institutional care unit because her only living relative is a sister with whom she does not get along well.)

New builds and older places that have undergone significant refurbishment display characteristics that align with what is stipulated in the legislation. The norms, however, tend to focus almost exclusively on issues of size of spaces, in view of a circulation free of obstacles that promotes the use of space as independently as possible by the residents. Being up to code is a condition for having a license to operate, therefore all institutions exhibit the corresponding certificate, as required by law, in the reception area. What the legislation does not define are the aspects of design and organisation of spaces that go beyond size and that can facilitate, or hurt, the enjoyment of rights such as the right to privacy.

The most modern facilities among the visited institutions offered a paradoxical picture at times. Although very modern and well-equipped at sight, they showed features that could hardly be considered adequate. One example of that is the placement of bathrooms across the corridor of the bedrooms, rather than next to them and preferably with direct access from inside the bedroom. This is the result of a design of spaces focused on the function rather than on those who are going to use the space. In one of the visited units, the expert saw how residents would circulate in and out of the bathroom at bathing time, walking naked and as part of typical block-treatment from the staff. One other example is the excessive use of glass, certainly a modern architectural feature that one finds in contemporary buildings but that may create inadequate solutions. In one of the visited institutions, the glass walls of the bedrooms allowed full exposure of the residents across bedrooms and to those circulating outside in the surrounding area of the building.

Space can in fact offer opportunities and create obstacles to autonomy and participation. A lot is still to be done to comply with a more comprehensive understanding of what autonomy and participation entail. Details such as the height of the reception desk in some places, not allowing someone sitting in a wheelchair to have a clear visual line to whoever is at the reception; or the height of information panels, in most cases completely inappropriate to those in wheelchairs; or the opening system of some doors, very challenging to all those who may have hand-grip impairments; these are features still commonly found even in the most modern facilities. To a certain extent, this reflects a culture of care where the interpretation of what a rights-based approach means is still quite limited in its scope.

Examples that deviate from this were found in two institutions, each with some unique elements of history that explain their choices in terms of layout and design of spaces.

In one case, the founder of the institution had some personal relationship with an architect that is nationally recognised for his work in healthcare units and nursing homes for older persons, and apparently someone with a strong sensitivity for issues of accessibility and autonomy. The layout of the residential care unit in this case shows some unique features that are rarely found in this type of institutions and that concur to promoting autonomy and participation: handrails along all corridors; opening mechanisms of doors and windows that facilitate independent use irrespective of physical limitations of the user; smooth inclination of all floors allowing for an easy circulation even if in a manually driven wheelchair; rooms equipped with a system of air conditioning independently controlled and allowing customisation of room temperature according to the preferences of whoever is inside.

In the other case, the promoter of the residential service is an organisation that was originally created to advocate for the rights of persons with disabilities and that still keeps a very active presence in the public arena as an advocate for the cause. The choice here was radically different from everything else found in other institutions. The institutional care facility comprises 14 fully equipped flats, distributed around a central building where common services are located. Although services offered follow the same typology of the classic institution, the layout of spaces involves staff moving around and delivering support as needed inside each flat rather than residents moving around spaces with pre-defined functions. Furthermore, each unit is fully self-serviced and therefore prepared to offer a high level of personal and private use by the respective residents.

Personalisation of spaces

From a human-rights perspective, depersonalisation is one of the most criticised aspects of the institutional care model, usually involving the removal of personal possessions, signs, and symbols of individual identity. A meaningful relationship with the space where one lives is built, among other things, around the opportunity individuals are offered to turn space into their own.

In all institutions visited, the management was aware of this important dimension of life in institutional settings and declared, with one exception, that the respective institution offers to residents some opportunities for personalisation of spaces, especially in the bedrooms. It was possible to confirm, in fact, that apart from one case, bedrooms were decorated to the liking of the residents and their families. In many cases, the bed linen was brought from the resident's original place of residence, alongside other personal objects, ranging from photos and paintings to religious objects, clocks, radio devices and others.

The opportunities for personalisation, however, have clear boundaries, and tend to remain confined to the space of the bedroom and do not apply to other areas of the residential unit. Outside the bedroom, the norm remains that of rigidity of routines[4] and block treatment[5] that tends to erase marks of individuality.

> *T. insisted for a long time she wanted to have her own bedroom. In her words, having her things and a place to call her own was very important. She was recently assigned an individual bedroom and she is happy about it. T. loves sports and wants to have some home-gym equipment to do her activities but that is unfortunately not possible. She has one indoor cycling bike in her bedroom but there is no more space for a treadmill, which she would love to have. Putting it somewhere else is not an option because all other spaces are for collective use. T. was very vocal about how important it is for her to have her things and how she dislikes the fact she cannot.*
>
> (Female interviewee, with mild developmental disability and visual impairment. She lives in the institution because her family is not available to support her in her daily life.)

One important aspect of personalisation is how it creates room for attentiveness and particularism in how residents interact with the staff. In the biggest residences, more depersonalised, the uniqueness of each resident is not only dissolved in the physical space but ends up being dissolved in how residents interact with the staff.

The visited institutions, that showed more rigid forms of organisation of space, with a clear division of functions (and time) translated into space, were the ones only allowing personal marks in space inside the bedroom. This comes hand in hand with the fragmentation of the identity of residents, that maintain some individual displays of individuality inside their bedrooms (although having to negotiate them, since most bedrooms are shared), but that tend to lose it once they step outside. Indeed, outside their bedrooms, residents end up dissolving in a series of procedures that promote block treatment and some distance from the staff.

In summary, the findings suggest the coexistence of apparently opposing trends in the living conditions found in visited institutions, although not necessarily translating into such clear cuts in terms of the promoted model of care, and in terms of the impacts they have on the lives of residents if analysed from a rights-based approach.

On one side, there are institutions that have engaged in significant efforts to modernise their facilities, proudly presenting them as a relevant step forward in securing the best care for their residents. On the other side, the expert found institutions that keep struggling to overcome the deficiencies of worn-out ill-adapted spaces that offer sub-standard conditions to residents. For the second group, the path of modernisation of facilities seems to take all the space in the debate about changes in the residential care service, with a strong belief that building a new and modern residence will be a guarantee for the delivery of a service that safeguards all rights of residents. The urgency of securing the resources to build new facilities completely overshadows any other aspect of life in the existing facilities, as if their temporary nature legitimises the absence of any other intervention. The first group, however, shows how misleading the path of modernisation may be. In fact, in too many cases what the expert found was a modernisation frenzy that remains rather oblivious to some important dimensions of rights. Issues such as inclusive design, promotion of autonomy and respect for privacy, or integration and participation in community life, are insufficiently addressed, even in the most modern facilities the expert has

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[4] Rigidity of routines refers to fixed timetables for waking, eating and activity irrespective of personal preferences or needs.

[5] Block treatment is a term used to designate processing people in groups without privacy or individuality.

visited. Additionally, modernity of spaces does not offer any automatic rupture with the core elements of the institutional care model where block treatment, rigidity of procedures, social distance to staff, depersonalisation, remain the norm, as the following sections will explore further.

2. Personal autonomy and choice

One of the main concerns about institutional care is how it inherently limits persons with disabilities from exercising the right to choose where they live, how they live, and with whom they associate. The expert's analysis focused on how institutional life is organised in visited institutions to safeguard opportunities for individuals to make choices and manage autonomously aspects of their lives. The expert looked at both the simplest areas of daily life (e.g., what to dress, when to bathe, what TV show to watch, when to eat, etc.) and to other more complex dimensions of life such as financials, treatments and therapies, activities, relationships, etc.

The general conclusion after visiting the 11 sampled institutions is that the way most operations are run coupled with a culture of care still anchored in disempowering understandings of disability leaves very little room for residents to exercise choice and be autonomous. Even the cases where the model of service provision is anchored in principles of autonomy and freedom of choice stumble against organisational and regulatory obstacles that impede the full realisation of those rights.

In regards the operations side, block treatment combined with a very rigid segmentation of time to perform a sequence of tasks limits personal autonomy and choice. Speed is a major hurdle for both staff and residents, albeit with quite different implications. Shortages of staff pressure caregivers to work fast and look for optimal ways of work organisation that deliver results, even if that involves dissolving the individual in what sometimes looks like an assembly line. This leaves little to no room to adapt the modes and the rhythms of personal assistance to the characteristics of the residents, which in turn limits substantially their opportunities to train for autonomy.

> *P. states that the staff working in the residence to take care of residents is not enough. On top of that, there are many episodes of absenteeism, which makes things even more difficult. At bathing time there is not enough staff to take care of baths and keep an eye on those residents who stay in the common room. What the team of caregivers at service do is keep the door of the bathroom open so that they can hear what is happening outside and keep an eye. They divide the bathroom into three stations: bathing, drying, and dressing. That way they can have 3 residents inside the bathroom and speed things to be able to bathe everybody quickly and with so little staff.*
>
> (Caregiver, female. She has been working in the institution for more than 10 years.)

The effects of the procedural aspects are amplified by the resilience of some social representations about disability and more specifically about the capacity of persons with disabilities to exercise choice, which ends up legitimising ways of doing things. Two aspects have stood out in the interviews with staff at both the operational and the management level: the belief that persons with disabilities, and particularly those with intellectual disabilities, are not able to make the best choices and need someone to choose on their behalf; the reproduction of a child-like status when describing what is best for residents, often portrayed as vulnerable and requiring protection. These two combined, offer the rationale for what constitutes in many aspects a clear limitation of the individual right to choose about aspects of life.

Interviewed staff are aware of the right to freedom of choice as a principle that should guide care provision in institutional settings. In fact, when probed to discuss how in practical terms is that observed in the daily life of the institution, most interviewees were able to verbalise how important it is allowing residents to choose and express their preferences. They would even give examples, typically concerning choice of clothes and choice of activities. However, sentences would always lead to 'but', articulating some explanation to the need of limiting the principle of freedom of choice.

> *V. is the director of operations in the residential unit of one of the visited places. He states he considers that residents should be allowed to choose what they dress, but he continues: "Of course, for most residents this does not work because their taste in terms of colour choice and combining pieces is very limited. And it is important residents look good. So, we let people choose but then we tell them that their choice of clothes may not be the best because red and pink do not go well together, and we help them choose something else".*
>
> (Director of a care facility, male.)

Days are organised in a standardised manner and residents have expressed their discontent about the implications of such an approach: fixed menus, fixed bathing times, fixed wake-up and sleep times, fixed schedule for leisure activities, shared spaces where there is no opportunity to do what one prefers to do – these are all elements of a rigid routine that tends to depersonalise residents and therefore not acknowledging their status as individuals with individual preferences and needs.

Example 4. *An institution has installed TV sets in each bedroom when the Covid-19 outbreak demanded the implementation of safety measures in institutional care facilities that would keep people distanced. Till then, the only TV available was in the common room, shared by all residents. This was something that some residents did not like because they prefer to watch certain types of TV shows different from the ones that would be available in the common room. All interviewed residents were extremely happy about having a TV set in their own bedroom because that allows them to choose what they want to see on TV.*

Participation in activities of daily living is generally very limited. This is explained by directors of residences as the combined result of the type of disabilities residents exhibit, on one hand, and of the need to guarantee their safety, which would be at risk if they were allowed to take part in some aspects of daily living. One example of such is the fact that the kitchen is off-limits in almost all the visited institutions. The only exceptions were the residences that operate in smaller buildings that are for residential purposes only. In all others, kitchens operate as industrial kitchens, catering for the needs not only of the residents but of those attending the CAO. This certainly contributes to the school feel one has at mealtimes. Participation in preparing food, setting the table, doing the dishes or others is something that is not part of the life of residents in most facilities as that is incompatible with the large-scale routines implemented. Interviewed residents have expressed as one of their biggest wishes to be able to have their own house where they could take care of things the way they like and cook the food they like.

Example 5. *An institution serves meals in a common dining room but offers windows of time for meals so that residents retain some control over when to have their meals and to allow individuals to organise their own routines according to their preferences. Breakfast is served up to 10 a.m. on weekdays and up to 11 a.m. on weekends. Dinner, in turn, is served between 7 and 9 p.m.*

The lack of opportunities to engage in aspects of daily life activities also limits the opportunities to get some training for autonomy. In fact, the notion sounded strange for most of the interviewed staff who have described living in the institution as the best and final living arrangement for the residents. Institutionalisation is still addressed as an almost irreversible status and therefore training for autonomy in preparation for transition to community-living is not a reference for the delivery of care services in the institutional care facility.

Families of residents in general do not want anything different from the model of care provision that institutions offer and consider it is the best to meet the needs of their institutionalised relatives. For most residents who have close ties with their families, the living arrangement prior to entering the institution is described by relatives as very similar to the one found in the residence in terms of opportunities to exercise choice and foster autonomy. The shared views about disability among relatives still reproduce the child-like approach that considers individuals as not only needing assistance and protection to do all things of life, but also as incapable of making good choices and taking good decisions. All evidence points to life in the family *milieu* prior to institutionalisation not being that different in terms of limitation of choice and autonomy, which probably explains why relatives were not worried about these dimensions when probed to talk about the opportunities their relatives were offered to exercise choice and to control aspects of their lives at the residence.

This topic, however, is not just the result of an attitudinal context. It is also the result of the material aspects of service provision, namely regarding human resources. One of the visited institutions, as already discussed in the previous section, offered a good example of how space could be organised to promote personal autonomy and choice providing personal residential spaces that largely mimic the environment of a regular residential flat. However, autonomy is about getting the needed support to perform activities of daily living. In other words, and as an example, having a kitchen available in one's flat for personal use does not mean that the individual can effectively use it. If that individual has limitations in motor skills, he/she will need the support of a third party to be able to use his/her kitchen. What the expert could see in one of the visited institutions is that, although organisation and layout of space is very much focused on fostering autonomy and choice, limited availability of support to allow for an individual use of available facilities means that, in practical terms, autonomy and choice face obstacles the individual will not be able to overcome.

One other aspect observed in many of the visited institutions was the relative lack of flexibility in the organisation of occupational activities during the day. Routines unfold along a pre-defined script of activities and schedules. Typically, residents do not participate in the elaboration of this script and must conform with activities decided by the technical staff. The classic routine of those living in institutional care is leaving the residence early in the morning to go to the CAO and returning towards the evening. In the sample of 11 visited institutions, that was the case for 219 out of the total 320 residents (around 68%). At the CAO the dominant model is that of pre-established activities, typically involving the distribution of individuals across activity rooms. Opportunities to do preferred activities are scarce and opting out is strongly discouraged.

During the interviews with residents, this aspect was identified as a cause for some discontent. Activities such as painting and doing collage are common but for many residents are not satisfactory. Some interviewed residents have declared that they would rather do something else, namely having a job, but cannot.

For a large portion of residents, however, going to the CAO is not an option. On the one hand because often institutions do not have enough places available at the CAO to accommodate all residents. On the other hand, because some residents are considered too dependent or having very severe intellectual disabilities that make it inadequate their placement at the CAO. In the visited institutions there was a total of 90 individuals (around 28% of the total residents) in this situation. For these individuals days are lived entirely inside the institution, with participation in some therapeutical activities defined according to the needs and characteristics of each individual.

In summary, it has long been argued that institutional care tends to be characterised by depersonalisation and rigidity of routines (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), as well as by block treatment (processing people in groups without privacy or individuality). The sampled institutions visited by the expert still offer ample evidence to support such claims and although the discourses are often aligned with the principle of safeguarding choice and promoting autonomy, the practices are not. This is the most relevant conclusion to highlight – although for a vast number of residents, choice and autonomy were denied at the very fundamental moment of choosing where to live (for the majority, living in the institutional care facility was not a choice but rather something imposed on them), that should not mean forfeiting entirely the right to choose and decide on the smaller aspects of daily life. This is a domain that institutions still struggle to accommodate within a care provision model that tends to dissolve individuality.

3. Family life, personal relationships, and social contacts

The right to enjoy family life, to form a family and to engage in meaningful personal relationships and contacts with other members of the community is a critical aspect for the enjoyment of life of all individuals, with or without disabilities. In the institutional care facilities visited by the expert, the dominant characteristic seems to be that of closure. This was further exacerbated by the Covid-19 pandemic, but even before the pandemic it was what defined the normality in most of these places.

One of the aspects that contributes to this feeling of closeness is the fact that all institutions offer multiservice and therefore the residents in the institutional care facilities are also the clients of other services, typically of the CAO. Life tends to revolve therefore around the residence and the CAO, very often both operating in the same building. The distance between the place of residence and the place of occupational activities is often a ride in the lift or crossing a corridor.

This model of organisation of services not only closes spaces, but it also tends to confine relationships to those closed spaces. Residents engage in relationships with other residents, who are also colleagues at the CAO. The most these relationships can extend is to users of the CAO that do not stay in the residence. In any case, relationships tend to revolve around the ecosystem of the service provider.

Visitors are very rare in most institutions. In fact, when relatives come to the institution, it is to take the residents to the family home for a weekend or a short break and not to visit the home of the resident. In most cases, the residence is designated by both residents and their families as "the school". The model seems to be close to what one would find precisely in a boarding school with very limited opportunities to engage in meaningful relationships outside the institution. In all but one of the visited institutions there are no dedicated places for families or other visitors. Weather permitting, in some institutions the outside space can offer some opportunities for residents to be alone with those who visit them. Indoors, that would not be feasible, since all living rooms are shared and for the use of all residents, and most bedrooms as well.

Opportunities to interact with people from outside the institution are further limited in some cases by some rigidity in visitation protocols. The most extreme cases were of one institution where there is a fixed 1-hour period per day for visitors to visit residents, or one other where visits can only take place on Sundays being complemented by one phone call the resident is entitled to receive on Wednesdays.

Participation of families in the lives of residents while at the residence is very limited and largely subdue to administrative protocols. The legislation imposes some mechanisms of participation of families, namely their participation upon admission in the design of the personal care plan, as well as their involvement in the periodic revisions of such plan. All interviewed relatives confirmed that they had met with the director of the residence upon admission of their relatives and that they had signed a paper with an assessment of needs and a plan of care. They have also confirmed that every year they receive, at home, a paper to sign with some information about their relatives' progress. For many this is experienced as getting the grades record from the school. Some interviewees talked about this as the annual evaluation of the resident. Participation beyond this rather bureaucratic rituals is absent. Most interviewed relatives did not have any information about other possibilities to participate in the life of their family members at the residence, beyond the celebrations organised on occasion of Christmas, Easter, or other celebratory dates across the year. The dominant feeling among relatives is that once the resident is admitted to the institution they hand in control.

The layout of spaces certainly poses considerable constraints on possibilities of developing personal social networks beyond those living and working at the institution. As the expert could confirm in the institution that has organised space around the concept of individual flats, the fact that residents have their own residential space, for individual use, allows them not only to have visitors mimicking what happens in the life of an average citizen that can host friends for dinner, but also allows a more intense engagement of relatives in the lives of residents, including assisting them in areas that in other institutions only staff will be allowed to do.

Example 6. *One of the visited institutions allows residents to have visitors in their personal residential spaces at their discretion. Similarly, residents are free to go out at any time. The only rule in place is that residents warn the manager in advance due to liability issues. Residents in this institution manage to keep a social life outside the institution that contrasts with what was observed in most other institutions.*

Generally, and based on evidence collected for the majority of visited institutions, personal relationships besides those with the family are primarily established as stated before among residents or among residents and users of the CAO. Discursively, the expert could identify a clear alignment with a rights-based approach, with care managers describing as a right the opportunity to engage in meaningful relationships, including relationships of a romantic nature and of a sexual nature. The practices however showed that for some institutions this is merely a discourse and not a reality. In some cases, limitations to engaging in relationships of a romantic nature are explained by the limitations imposed by space and its collective nature. This is particularly the case for sexual relationships, that directors of residences see as very difficult since bedrooms are shared and there are no extra spaces for individuals to engage in sexual activities in conditions of privacy.

Relationships with people from outside the institution are considered as very difficult to accommodate since not only there are no available spaces but also due to security reasons.

Space and logistics constraints, however, are not the single variable accounting for the limitations in opportunities to engage in romantic and sexual relationships. The 'institutional climate' and the resilient understandings of persons with disabilities as asexual bodies are both important variables to consider. In some cases, allowing for romantic relationships to evolve among residents is seen as posing some risks. The rationale is that relationships may be interrupted and that will generate hostility and tension in the residence.

As far as caregivers are concerned, many interviewees were not able to acknowledge that persons with disabilities are able to engage in meaningful romantic and sexual relationships. In fact, in some cases, sexual activity of residents is seen as something that corresponds almost exclusively to the expression of natural instincts, that often gives room to rather unhealthy behaviour, as many residents, according to the staff, look for self-gratification and look for pornography online. This is seen as something that needs to be controlled as it is considered unhealthy for both the resident that engages in such behaviour and other residents that may witness it.

In summary, residents living in the institutional care facilities visited by the expert seem to have relatively small social networks, mostly confined to interactions with other residents, users of the CAO and the staff. Family relationships are also relatively limited and take place mostly outside the spaces of the institution. Involvement of families in daily activities of residents is marginal. Opportunities to engage in personal relationships and to plan for family life are little. Even in those institutions where there is some tolerance from the management towards the romantic involvement of residents, family formation and marital life are not included in any aspect of development of residents and are not considered in terms of organisation of spaces and activities.

4. Citizenship/rights

The topic of citizenship and rights relates to a much broader discussion than the one the expert can accommodate in this report, as it mirrors the *status quo* of disability in society at large. The expert has focused her analysis on aspects of organisation and procedures of institutional care facilities that create opportunities or limitations to the exercise of rights of persons with disabilities and for the realisation of their full potential as citizens.

We live in a time of unprecedented recognition of the rights of persons with disabilities. This is quite visible across a wide spectrum of social actors, including those in charge of managing the care facilities and those with team coordination responsibilities. In some institutions, however, the discourse apparently tuned with principles of rights and freedoms was coupled with a low level of familiarity, or even complete ignorance, concerning the UNCRPD. Additionally, and although discourses are important, full citizenship will only be achieved when the conditions for the realisation of rights are met. The rationale for the questions raised in this section stems primarily from this statement.

A first aspect to highlight includes access to information on rights, duties, procedures, and rules related to the operations of the care facilities. Existing rules established by the regulator are quite clear about the need to have all pieces of documentation related to the operations of the care facilities in public exhibit and accessible to all. Visits to sampled institutions allowed to confirm that in all, without exception, at the entrance hall there is a dedicated place where all documents required by law to be on display were in fact on display. This does not necessarily mean they are available for consultation, at least not without the intervention of the staff. In almost all institutions, documents are on display behind a closed glass window. In only 8 out of the 11 visited institutions, internal regulations were available for online consultation. Relatives of the residents involved in the process of admission are handed in upon registration all the documents that constitute the legal framework of the operations of the institution (admission rules, regulation of operations, rights and duties of residents, information on payments), but generally speaking the residents themselves were quite unaware of these documents.

This insufficient access of residents to information pertaining their rights as residents, spreads to broader areas of rights. As discussed before, those in institutional care tend to live in a relatively closed setting and opportunities to access information, support and advocacy are very limited if any.

One important mechanism to secure some open channels for residents to connect with outside actors and have access to information, counselling, and advocacy would be to allow access to the Internet. It is important to highlight, for example, that contact with the Ombudsperson in Portugal can only be done by phone or by email. In both cases, the communication channel must be secured for residents to have access to this important instance of representation of their rights. That is however not the case in some of the visited institutions.

In several of the visited institutions, residents do not have access to the Internet. The reasons for that range from technical problems and associated costs to resilient views of persons with disabilities as lacking the capacity to make a responsible use of Internet. During the interviews, it was mentioned several times the topic of the risks associated to granting access to the Internet. Interviewed individuals stated their concern about the safety of residents if left free to navigate through the web, especially because of people that use social media platforms to trick and lure those that are more vulnerable.

The topic of rights and citizenship is probably the most sensitive of all for the visited institutions as it clashes, in principle, with the traditional model of care one finds in the social care services sector in Portugal, largely influenced by a charity approach, typically serving disabled people rather than persons with disabilities, and traditionally rights averse. In some institutions, it is possible to identify some attempts to change this situation and evolve towards participatory ways of service delivery. It is likely it will take some time to see the effects of such experiments at a bigger scale.

Example 7. *Two of the visited institutions had a group of representatives that meet regularly to discuss issues related to the functioning of the residential care facility. The group is described as some sort of equivalent to a condominium assembly where residents have the right to discuss and vote for changes in how things are organised and implemented in the house. Each person has one vote and decisions are in principle binding for the management. In one of those institutions, the group of representatives is even part of the formal structure of management of the facilities. In that institution, internal regulations set as mandatory the consultation of the group of representatives in all issues pertaining the management of the institutional care unit.*

The second aspect to highlight concerns the lack of support for, and barriers to, "community presence". Rights of persons with disabilities and the realisation of their full potential as citizens also concerns their place in the community next to other citizens and taking part in the public space. To participate in the community as full citizens, persons with disabilities need to be present in the community and there are still many barriers to this, the most obvious of all the fact that residents in the visited institutions are living separated from the community. The point of the analysis was to assess to what extent institutions safeguard the right of their residents to participate in the community as citizens, despite the specificities of their living arrangements. Directors of institutions were asked, for example, whether residents could participate in electoral votes, and all stated that if they wanted, they would be taken to the designated place to cast their vote. The actual participation in voting was only signalled in 2 of the 11 visited institutions.

Participation in discussion forums or access to information about aspects of the local community life are absent from life in institutional care settings, and 10 out of 11 visited institutions just confirmed that. As discussed above under living conditions, this situation is significantly influenced by the location of residential care facilities. However, that alone does not fully explain the separation from the community, which for all purposes is a facet of limitation of the individual's existence as a citizen. There are also attitudinal barriers to participation, from society, and reproduced by the institutions and their staff. On the one hand, persons with disabilities are primarily seen as in need of 'care', which undermines seeing them as autonomous individuals in full possession of their rights as citizens. This comes coupled with the assumption that it is legitimate, even necessary, for other people to make decisions on behalf of persons with disabilities. Therefore, they are not recognised as actors in community participation but rather as recipients of other people's community participation. The result is that persons with disabilities end up being treated as not 'belonging' to the communities in which they live, which significantly undermines their place as citizens.

Moreover, full participation in the community requires the community to be a space that is inclusive and where all can take part irrespective of their unique characteristics. This includes issues of accessibility and circulation. Even in the one institution where the expert met residents with very high levels of engagement in political and social life of the community, actual physical participation often faces obstacles that prevent individuals to be full members of society. Sidewalks, public transportation, accessibilities in public services are some of the areas that interviewed residents have signalled as still lacking adequate conditions to allow for a full participation of persons with disabilities.

5. Development and health

Overall, this is one dimension where the bureaucratic procedures tend to dominate to respond to norms set by the regulator rather than reflecting the incorporation of a person-centred model in how support services are run and delivered.

What prevails in the visited institutions is a model of care rather than a model of support. All institutions keep, for each resident, and Individual Plan (IP). The IP, at least in theory, is designed to tailor services to the needs, preferences, and expectations of residents and always having in view the promotion of autonomy. In practice, they do not seem to go very much beyond the bureaucratic procedure that is mandatory by law. The expert did not have access to any individual plan due to data protection concerns. However, when interviewing the relatives of residents, and although the individual plan is the result of a co-design approach, individuals declared they knew about the existence of such a document, that they had signed it on the date of admission but there was no report of significant involvement in its elaboration. The impression is that the elaboration of the IP is dominated by the coordinating staff and with very limited participation of residents or their relatives. Although these plans are to be reviewed periodically, upon consultation with residents and their relatives, interviewed relatives stated they would receive every year, at home and by mail, “the papers” to sign. For most interviewed relatives, the process resembles, as stated before, getting the school grades.

A model of support targeting individual development involves developing personal goals, selecting resources, and developing support strategies in response to support needs of persons with disabilities. It also involves creating opportunities for everyone to reach their full potential. The guidelines offered by the regulator on how organisations providing residential care services should approach the IP are quite clear and include domains of personal development (personal relationships, self-determination), well-being (emotional, physical, and material) and social inclusion (employability/occupation, citizenship, and rights). The regulator goes to the extent of offering examples of what would constitute components translated into planned actions of an IP in different domains of development. Although the expert, as said before, did not have access to the IP of any resident in visited institutions, core domains of personal development, even if included in the IP, certainly do not translate into the daily routines of residents. Block treatment is the norm and activities are organised for the group, with little room to accommodate specific needs.

> *B. lives in the residential care facility because she comes from a dysfunctional family, and it is not safe for her to stay at home with her relatives. She was placed in the institution by the court. B. has attended the regular school and knows how to read and write. She does not like to join some of the activities because she feels she knows more and feels bored. She says she would like to continue studying and is afraid she will forget how to read if she does not do it regularly.*
>
> (Female resident with moderate developmental disability and diagnosed psychiatric disorders. She lives in the institution because her family is dysfunctional, and she has suffered abuse since childhood.)

The expectation from the regulator is that the IP is used as a guiding instrument for caregivers in their daily work, assuring residents will have more rights and control over their lives, that service provision rests on support processes, enhancing a person-centred approach to residential care services. This is, however, quite far from what was observed in the visited institutions.

In what concerns the specific domain of health promotion and healthcare provision, the situation observed in the visited institutions raises some concerns.

Healthcare to residents is managed within the national provisions for healthcare for the general population. Residents will be escorted to regular doctor appointments in hospitals or clinics and taken to the emergency room in exceptional situations requiring emergency care. This domain is not always included in the services that the institutions provide, and in principle they prefer it to be secured by families. These, however, are not always available to go with their relatives to the doctor, and the staff of the residence must take upon them that role.

Institutional care facilities are not required to have in their list of personnel healthcare professionals. This is something that most institutions tend to pinpoint as a source of problems since in many cases residents have chronic health problems, some due to their disability, while others couple disability with mental health conditions that require medical attention and intake of medication. If regular healthcare is generally secured, dealing with emergency situations, namely those associated to psychotic episodes and crisis is more challenging.

Most residents in the visited institutions take daily medication and caregivers oversee giving the medication to residents, according to what is specified in the respective IP and as part of the block treatment routine. This also includes support in the more extreme cases where nasogastric feeding, cleaning of bruises and pressure ulcers, or others of the sort is required.

6. Participation in the community (employment, education, leisure, and cultural life)

The residential care facility and the occupational centre (CAO) are at the epicentre of residents' lives. Days are relatively similar, during the week, and alternate between the hours spent in the residence and the hours spent at the CAO. Transportation, in the cases where the two units are geographically apart, is secured by a fleet of vans transporting users of services. On weekends, when the CAO is closed, the day is spent at the residential care facility except for those occasions when the resident goes with a relative for a weekend out. For those not attending the CAO, life is spent entirely inside the institutional care facility. It should be noted that among the 320 residents in the visited institutions, only 10 (around 3%) were engaged in some type of job or in education/training. And among these 10, half are living in one specific institution. In other words, it is a very rare situation.

When asked about what the advantages for the residents of being institutionalised were, most managers of the visited institutions highlighted that if not in the institution, the residents would be very isolated in their homes. On the service provision side, in that sense, there is a very positive view about what it means to be in the institution. They firmly believe residents are better off there than if they were living with their families or in their homes. They consider that persons with disabilities that are living in the community are often even more isolated than those in institutional care settings, as they tend to stay home all the time.

This positive view, however, seems to contrast with what the residents have described themselves. Although some would mention their satisfaction about "having friends" in the residence, most interviewed individuals have also mentioned feeling bored on several occasions because "they do the same things all the time". Many complained they would like to be allowed to go out, and do not like to be closed inside all the time. This is particularly so at weekends, when the CAO is closed and when there is less staff at the residence.

Participation in the community was an expression used by most managers and technical staff of the visited institutions. However, it would be described more often as something they 'do' rather than something they 'are'. In other words, participation in the community tends to translate into organised forms of participation moderated by the staff, with a relatively narrow scope of activities being allowed and most of the times following the same principles of organisation of block treatment approaches. In practice, this translates into a series of "outdoor activities" and "field trips" to the community that are meant to break up with the routine of service provision: occasional visits to public amenities, trips to shops and walks outside in the city. In most cases, the staff accompanies the residents, controlling time, destination, and the logistics of the activity. Participation is rarely if ever part of the ordinary social life of the surrounding community and rather an activity that tends to be perceived by the staff as an element of service delivery. One preferred activity of residents is to act as consumers outside in the community, purchasing beverages or other small items, although this tends to take place under the control of the staff and according to amounts of money available to spend defined by the management. In only one of the visited institutions were residents in control of their money.

The model of participation in the community found was primarily that of "going out to see the community" (and be seen by it) rather than a model of full inclusion in the life of the community. Factors such as location, accessibility, and the overall attitudes of society towards persons with disabilities, are certainly important explanatory variables for what the expert found in some institutions. However, the driving force is still the dominant culture of care in place in most institutions. It puts the emphasis on organising activities rather than on individual projects of development and inclusion, and this limits considerably the scope and the opportunities of being included in the community of the residents living in the visited institutions.

The specific area of participation in the labour market was mentioned by many of the interviewed residents and pinpointed by some as a source of frustration.

> *D. lives in the residential care facility because his parents died and his sister cannot look after him and his brother, both with intellectual disabilities and both living in the residential care facility. He was placed in the residence against his will. He explained that before living in the residence, he used to have a job, at a bakery, and he liked it very much. He wants to go back to work and lives in a constant state of frustration because he cannot.*
>
> (Male resident with developmental disability and diagnosed psychiatric disorders. He lives in the institution with his brother, also with disability, because their only living relative is a sister that cannot take care of them.)

It must be acknowledged, however, that this is not just the result of cultures of care and views of disability. In one of the visited institutions, where the expert found very engaged residents, some with high formal qualifications, the main problem seems to be outside the institution. Although very supported in actively looking for a job, residents explained that it is very hard, almost impossible, to find an opportunity due to their disability.

> *G. lives in the residential care facility because she has severe mobility problems due to brain palsy. She successfully finished her master's degree and is actively looking for a job. She has been shortlisted several times and called for job interviews, but once potential employers realise her limitations, they explain it would be impossible to hire her since that would require adaptations of workplaces and equipment that they are not able to secure. G. feels very frustrated about this especially because she believes that if she could have a personal assistant the problem would disappear.*
>
> (Female resident with mobility limitations due to brain palsy. She lives in the institution because her mother is ageing and also because she wanted to be independent from her family.)

To set the context it is important to highlight that one of the conditions the expert has often found in the admission criteria set by institutions is the candidate being a user of the CAO. If someone is integrated in the labour market and has a paid job, that person will not be admitted as a resident in the institution in most cases. To a certain extent, being in an institutional care setting is understood as something for those that cannot be part of the labour market. This is probably why, in most cases, IPs do not include any disposition on integration in the labour market. Unless the IP is elaborated to include a personal project of development targeting transition to some form of independent living or community-based care, training and skills formation or supporting active search for a job are considered paradoxical within the type of service provided by the residential care unit. In fact, one can even see some conflict of interests in this domain since integrating a resident in the labour market could lead to the institution losing the individual as a client.

CAOs were often presented by managers of institutions as the equivalent to having a job for residents, as in the CAO the individual is said to engage in meaningful and socially useful activities. This is how the model is narrated, also in official discourses of representatives of national authorities. This however does not correspond to the observed reality and has been generating some criticism over the years. Recent legislation has been approved to induce some changes in the profile of activities offered by CAOs. They have in fact been renamed and are since 2021 designated as CACI – Centres for Activities and Capacitation for Inclusion. In most CAOs associated to the visited institutions, occupational activities involved arts and crafts, very much following the child-care approach, which could hardly be taken as some equivalent to a regular job. Although CAOs fall outside the scope of this report and although the expert has not collected evidence specifically on them, these readings could be extracted from the narratives of the interviewed residents.

7. Legal capacity of residents

In 2018 there was an important paradigm shift in the Portuguese legislation, politically presented as a response to Article 12 of the UNCRPD – *Equal recognition before the law*. It translated into a piece of legislation that passed in the national parliament in August 2018, and that states a principle of supported decision making in situations where individuals, due to illness, disability or behaviour are unable to exercise their personal rights and consciously make decisions[6]. Up to the passing of this law, people with disabilities would be deemed unable to make decisions, after a court ruling, and placed under guardianship and substituted decision making. The new law has therefore introduced a paradigm change from a principle of guardianship and substituted decision making, to one of supported decision making.

The gap between the spirit and the contents of the law and what the expert found in how institutions manage the implications of the legal status of their residents is, however, very big. What the expert found was a resilient model of care that assumes that persons with disabilities, especially those with intellectual disabilities and developmental disorders, are not capable of making good decisions and therefore need to be subjected to decisions made "in their best interest". In most cases, the change from the previous status of guardianship to the newly established scheme was formally done or is underway. In all cases, however, the person who would take the role of guardian before was now appointed as the person supporting the resident in terms of decision making. And although the new scheme envisages the participation of the person with disabilities in the decision-making process, in practice nothing seems to have changed, with residents not being offered any real opportunities to participate actively in decisions. Among the 320 residents living in the visited institutions, 232 (around 73%) are in the Adult Support Scheme and have an appointed legal representative. In most cases, it is the director of the institution that takes up that role.

When confronted with the topic, both managers, staff and relatives of residents seem to recognise the importance of empowering persons with disabilities and respect their decisions. Overall, all praise the new piece of legislation and what it means in terms of recognition of the rights of persons with disabilities. It is however empty rhetoric as most interviewed people would override this discourse of empowerment by concerns about safety and vulnerability, and by assumptions about the lack of capacity to make good decisions, which ends up legitimising the enduring guardianship approach in practical terms.

An additional trend that raises concerns is the fact that in many cases, the person nominated for the role of support in decision-making is the director of the residential care facility. This raises issues of potential conflicts of interest as the person that is supposed to assist the person with disabilities in exercising his/her rights is the person that represents the interests of the institution that is often at odds with those same rights.

This topic is one still marked by some paradoxes that ultimately seem to point to a fundamental understanding of what supported decision making really means. This is related to shared cultural assumptions about disability and persons with disabilities. The person with disabilities is still seen as someone that needs to be protected and safeguarded from the negative consequences of bad decisions that would naturally be made given the lack of capacity to decide, and what is ultimately perceived as poor judgement.

When addressing the topic of legal capacity during the interviews with directors and technical staff of the care facilities, the subject that was brought almost immediately by interviewees to the discussion was the management of money. This topic is clearly sensitive with most directors emphasising that they manage the money of residents but that they keep detailed records of all money that comes in and of all expenses. Some added that residents are kept informed about their balance sheet. The interviews with residents were inconclusive as many did not seem to know much about the topic. Some residents, however, were very well informed about their balance sheets and some could be quite detailed about it.

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[6] The Scheme of the Adult Support (*Estatuto do Maior Acompanhado*), approved in 2018, allows any person who, for reasons of health, disability, or conduct, is unable to exercise their personal rights fully and consciously or to fulfil their duties, to request the necessary supporting measures from the Court. Supporting measures may also be requested by the Public Prosecutor's Office, the spouse, the unmarried partner, or any other relative that holds inheritance rights. These measures involve nominating someone to support the person in decision-making processes – Lei nº49/2018 published on the 14th of August of 2018 available at https://dre.pt/home/-/dre/116043536/details/.

Among the visited institutions, only two have formally stated that they see a conflict of interests in the institution taking up the role of legal representative of the resident and refuse to consider that possibility. These are institutions where residents are either fully integrated in family networks or with full intellectual competence. Whether this position would be feasible in the absence of those two factors remains to be seen. Since there are currently no alternatives for legal representation, institutions will be forced to take that role, even if they genuinely do not want to take it.

8. Confidentiality, privacy, and dignity of residents

The subject of confidentiality, privacy and dignity needs to be addressed in relation to three aspects that must be considered to understand fully the current picture of life of persons with disabilities in the visited institutions.

Firstly, it is a subject that cannot be separated from the discussion about the physical space and some of the features already discussed in sub-section 1. The norm, as stated by the managers of the care facilities, is to have shared bedrooms – this is said to be the best arrangement since it matches the preferences of residents and offers efficiency gains, namely in terms of mutual support and monitoring. This was not necessarily confirmed by all residents, with several declaring to the expert they would rather have their own individual bedroom. In any case, the fact that bedrooms are in general shared by two and sometimes by three residents inevitably poses some limitations on the right to privacy.

In these shared bedrooms, wardrobes are also organised in a manner that does not put privacy at the centre: in some places, wardrobes are shared since there is not enough space to have individual wardrobes; in other places there are individual wardrobes, but none is locked, with no mechanisms in place to prevent undue access to one's possessions. In fact, it was confirmed by both residents and staff that there are several episodes of residents going through the personal belongings of other residents.

Spaces are primarily organised to promote communal life. The problem is that this seems to be a constant – communal life all the time, which translates into the absence of any dedicated spaces for residents to be with visitors or with other residents in a more private manner, or even alone.

Secondly, the expert sees some potentially bad practices in what concerns safeguarding privacy and dignity of residents as a direct result of shortages of staff. One of the most evident examples concerns routines of personal hygiene. Shortage of staff forces workers to look for strategies to perform the tasks that will invariably prioritise speed and the task that needs to be done rather than the dignity of residents. At bathing time, staff resorts to having several residents in the assisted bathing room, which is divided into three stations: bathing; drying; dressing. Residents rotate across stations with gains in time and with optimal use of the labour force available. From the perspective of the staff, overburdened with a variety of tasks they cannot handle, this solution offers good results in terms of performance. Little to no room is left for considerations about privacy, dignity, and any feelings on the resident's side. The individual is on display and the body is manipulated by the staff as if deprived of will or identity.

> *G. needs to sit on a wheelchair all day since she cannot walk. She is in full control of her bladder but needs to visit the loo very frequently due to kidney problems. Since she needs assistance to use the toilet, staff are called often to assist her doing so. They perceive this as too much and are always pressuring her to put a nappy. G. does not want this and feels very humiliated, but she will accept it most of the times, especially because she fears that if she resists, she may end up being left unattended when she calls for help.*
>
> (Female resident with mobility limitations due to brain palsy. She lives in the institution because her mother is ageing and also because she wanted to be independent from her family.)

All this relates, naturally, to the third aspect the expert sees as accounting for observed practices in terms of respect for privacy and dignity of residents – the overall culture of care in place. Probed to talk about how residents would feel about not having much privacy, or about how they would experience situations where their bodies would be more exposed, interviewed staff offered explanations where expressions such as "they don't mind", "they are very innocent and see no bad in the naked body" or "they are like brothers and sisters". This corresponds to persisting representations of the person with disabilities, especially the one with intellectual disabilities, as someone that is locked inside a permanent child-like status, used simultaneously to ground assumptions of incapacity but also to describe some sort of permanent state of innocence. In both cases, the expert finds a disempowering understanding of disability.

One manifestation of this dominant understanding of how a person with disabilities thinks and perceives the surrounding world as a child-like state of development, is the way staff talks about residents - in most of the visited institutions, residents are addressed by the staff as "the kids".

9. Personnel (hiring protocols, training opportunities, support mechanisms)

The styles of management of human resources in visited institutions are very similar which stems from the regulations in place both from the side of the regulator and in the social care services sector. Almost all visited institutions, with the exception of one, in Madeira, are Private Institutions of Social Solidarity (IPSS) which means that they must fulfil the rules in place to operate residential care facilities as set by the Social Security Services. These rules establish the minimum number of staff members in different categories that must be secured according to the number of places available in the residence. The sector of IPSS, coordinated at a higher level by a representative body, follows some additional rules agreed within the sector – one of the most important concerns the salary rates that are annually defined in a document that offers the salary reference for all institutions. All visited institutions pay salaries to their staff, in all categories, according to the minimum established in the salary table for the IPSS sector.

The immediate consequences of this system-wide framework are: i) shortages of staff in some residences; ii) low salaries leading to low levels of satisfaction with work among the staff; iii) hiring of unqualified care staff, often unemployed women who will accept the low salary and the post by lack of alternatives.

Shortages of staff are found in a more severe manner in the institutions that have a higher number of severely dependent residents. In some cases, some residents were described as requiring the permanent assistance from one dedicated caregiver. Since the regulations in place establish minimum numbers of staff irrespective of the specific needs of residents, institutions can be licensed to operate even if the number of staff members is insufficient for the actual needs of support. Since the amount of money that the Social Security transfers to institutions is also set at a fixed rate, irrespective of the severity of the need for support from the resident's side, institutions often struggle with shortages of available funding to go above the mandatory thresholds for staff and abstain from hiring additional workers. This, in turn, ends up translating into what the staff perceives as an excessive workload. All workers interviewed have mentioned the amount of work they are expected to perform, that they see as excessive with negative consequences to their health.

The workload, combined with the low salaries, are the cause for the narrative of discontent heard from almost all interviewed staff members. This is exacerbated among the caregivers, a group severely impacted by high rotation of staff and high levels of absenteeism. All together these deteriorate the working conditions and are likely to impact negatively the service provided to residents. The interviewed caregivers were very vocal about their discontent and a feeling of unfairness was dominant, especially in what concerns their pay level[7].

The management perceives the issue of personnel and human resources management as the biggest challenge institutions face. There was no exception to this view. All directors of visited institutions described as hard all attempts to hire caregivers, claiming the job of caring after persons with disabilities is not attractive, due to the low salaries and the heavy workload, which makes it very difficult to attract potential candidates. This is further aggravated by the working hours that are involved in working in shifts. The result, according to interviewed directors of institutional care facilities, is that the institutions cannot really choose candidates that show a better fit for the task but rather must take whoever shows up. This often results in a very poor fit that leads to early termination of the job contract from the side of the worker.

When asked about the training they were offered after being hired, most of the interviewed staff was not offered any formal training but rather learned from observing others and by doing. If one considers the generally low qualifications of the staff members in the group of caregivers, the absence of training and formal integration in the routines of the institutions raises some concerns.

In what concerns training opportunities and upgrades, although the interviewed directors stated they have implemented regular assessments of needs and offered regular training accordingly, the interviewed staff did not confirm it. The training opportunities the staff could remember attending concern first-aid training, self-care techniques and in some institutions, self-defence. In only one of the visited institutions, it was possible to identify training organised by the institution on subjects related to the UNCRPD. The technical staff engages more often in training, although most of the times by their own initiative and even at their own expenses as part of an individual strategy to enrich the personal CV.

Overall, what the expert found was a female-dominated workforce (82% of the total 290 workers in the visited institutions), especially in the caregivers' group, where the dominant culture of care sees the staff working at residential care facilities as a surrogate for the family. This partially explains some behaviour that could be considered paternalistic but that interviewed individuals narrate as stemming from affection and desire to protect residents.

10. Restraint and seclusion

Although the use of restrictive measures is subject to several laws and regulations, there are anecdotal reports of its regular use in institutions, which justified its inclusion in the observation protocol and in the checklist of the interviews. In this report, restrictive measures are considered those that limit a person's freedom of movement using physical force (physical restraint) or mechanical means (mechanical restraint) or by removing

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[7] The salary table negotiated by CNIS (*Confederação Nacional de Instituições de Solidariedade Social*) – The National Association of IPSS for 2020 can be accessed at www.cnis.pt. As an example, the salary rate of the director of a residence is set at a monthly gross of 1231€. A licensed psychologist with coordination roles will earn a monthly gross of 1148€. A first level caregiver will earn a monthly gross of 686€, while a third level will earn 647€. The minimum wage in Portugal for 2020 was set at a monthly gross of 635€. Some of the visited institutions were also running independent living centres and have hired personal assistants. These are seen by the caregivers working at the institutional care facility as their equals in terms of job description but are paid at a higher rate (on average between 800€ and 900€ gross, per month). This introduces some additional discontent about what is perceived as an unfair discrimination.

an adaptive device. Seclusion is a restrictive measure in which a person is confined to a location for a given time and cannot leave this location freely. Chemical restrictive measures concern the use of medication imposed on the person without his/her consent to induce a desired behaviour, typically calming down the individual and interrupting behaviour considered disruptive, aggressive, and potentially risky.

The expert could not observe actions that suggests the routine and widespread use of any of the restrictive measures outlined in the previous paragraph. The conclusions presented in this section rely almost entirely on the narratives of participants collected during the interviews. And those narratives seem to point to some inconsistency between the discourses and the practices.

In principle, and as described by the directors of institutions and by the technical staff, any form of restrictive measures may only be applied to prevent persons from harming themselves or others. However, that was also described as something rarely taking place since caregivers know residents too well and can, most of the times, anticipate disruptive behaviour before it takes place. Aggressive behaviour, tensions and conflicts among residents are described as a normal part of life in a collective living arrangement but directors and staff alike declare that those instances are managed resorting to communication strategies aimed at calming the residents. All directors and staff refused the possibility of any punishing approach being used and refuse the use of any space as a punishment or isolation room. The isolation rooms do exist in the institutions, but according to the interviewed staff they are for exclusive use in psychotic episodes or if some resident falls ill and needs to be isolated. The interviewed staff acknowledge the use of SOS medication as a mechanism of control of disruptive behaviour. They further explained that many residents have multimorbidity diagnoses, combining the disability with psychiatric illness, which requires the use of some chemical restraint on occasions. The doses, however, are perceived as very low, with mild effects. The medication is administered by caregivers, according to prescription, but there is no supervision by any healthcare professional. It was only in one institution that the expert has observed the use of permanent seclusion of residents. This is an institution that houses three residents with very severe mental illnesses and due to the risks they represent to themselves and others they have to be kept locked inside a cell-like bedroom. Although this is an extreme case that by no means represents the sector, it is a good illustration of one of the main problems institutions face within a system that offers insufficient responses in the area of mental healthcare. Institutional care facilities are not designed, and do not have the human resources, to deal with severe mental illness and placing individuals with such a diagnostic in these facilities is a violation of their rights, as it prevents them from getting the healthcare appropriate to their health conditions.

Contrary to the discourses collected among directors and staff, the narratives of some residents suggest that restraint and seclusion may be present in slightly more subtle formats. This probably explains why they are not understood as examples of restriction by the staff, but rather considered as a sort of normality in a culture of care that infantilises persons with disabilities. Residents reported to the expert that when someone misbehaves, caregivers may slap them in their hands or in their buttocks. Some others reported that they are punished and sent to their rooms and put in bed. Some reported being forbidden to use their personal mobile phones or computers for some time. In all cases, the examples are typical of a child-like approach that punishes bad behaviour by removing the object of pleasure (like if it was the toy of a child) or by confining the individual to a separate room to have some time-out and reflect to repent. The expert heard some reports on excessive use of violence by some staff, but these were situations that were generally acknowledged by the management of the institutions and dealt with accordingly.

11. Complaints and investigations

Complaints and investigations seem to be another area dominated by protocols. Institutions keep detailed records of any incident in a file known as the “Episode file” (*Ficha de ocorrência*). This consists of a template where the staff records any situation that involves out-of-the-ordinary behaviour of residents or staff. A detailed description of who was involved, in what capacity, as well as a written description of how the staff and residents involved explain and understand the event is required. The staff with coordination responsibilities then analyses these records and actions deemed necessary are ordered. Most of the times, however, the records do not lead to anything concrete and are rather an administrative procedure imposed by regulations in place. Their format resembles the records used in schools for reporting on bad behaviour of students. On the other hand, when the episode requiring a written record involves some staff member, there is a very unequal distribution of power between staff and residents in what concerns each’s capacity to control the contents of the report, as this is always filled in by the staff.

Questions and complaints have nowhere else to be expressed besides the institution and the expectation from the management side is that residents raise issues with the director of the care facility or with a staff member. The potential conflict of interests in this situation was dismissed by interviewed directors. The expert has asked, in specific, if there was any concern about residents feeling afraid or discouraged to raise complaints about the institution if those complaints are to be presented to the director of the institution. The answer was a straightforward no, from all interviewed directors. Many have mentioned that residents can always use the suggestions box at the entrance if they wish to remain anonymous and that is seen as solving the problem.

Interviews with relatives were also revealing as this was a topic that most interviewees could not describe in detail. Some interviewed relatives were uncomfortable with the questions and stated they never felt the need to formalise any complaint. Others added they would not know who to look for besides the director of the residence if the need for a complaint ever shows up. Overall, relatives sounded not informed about protocols in place. However, they all confirmed that when there is an episode involving their relatives, they are informed about it.

Overall, what is missing in most places is an independent level of assessment – complaints and investigations are managed in-house, which hardly qualifies them to be labelled as neutral.

12. Admission and leaving rules / aftercare

Regulations and practices concerning admission and leaving the institution show some fundamental aspects of the social care services sector in the field of disability and offer some additional evidence about the size of the challenges ahead if these institutions are to fully embrace a rights-based approach to service delivery.

The protocols in place concerning admission are pretty much the same across all visited institutions and are outlined in the Regulations Document of each institution (*Regulamento Interno*) as required by the regulator. Criteria for admission include a combination of needs assessment, evaluation of fit of candidates to the institution and place of residence, with priority given to those applicants living in the geographical area of influence of the institution. Needs assessment includes not only the assessment of specific needs for support of the resident, but also the assessment of the social conditions of life of the candidate, with priority being given to those at risk of social exclusion and/or with no family support. In most cases applicants must also attend the CAO.

In practical terms however, decisions concerning admission are not the result of a very transparent process, as they are almost fully controlled by the institutions. Under the collaboration agreements institutions sign with the Social Security Services there is the possibility of some places in the institution being reserved for placement directly by the Social Security Services. Usually these are the places taken by individuals that are ordered for institutionalisation by a court or signalled by the Social Security Services as being in a situation of eminent risk – they are labelled by the staff as the Social Cases (*Casos Sociais*). The number of those reserved places however is residual, with the institution controlling admission for most places available.

Although the expert has no evidence of preferential admission episodes, there are ample anecdotal discussions about the way the social care services sector operates and how admission is the most evident area of patronage and influence based on social capital. The way the system is designed gives some space, at least, for some concerns about the possibility of admission rules being bended and based on particularistic criteria that benefit some while excluding others.

Leaving rules are a different topic since if something can be highlighted is the absence of protocols to deal with situations when residents leave the institution, namely in what concerns aftercare. The only situation anticipated in the Regulations Document is the case of residents that end up not adapting to the institution, or that violate rules leading to the need to move them to an alternative institution better prepared to accommodate their needs. Planning in advance the possibility of a resident leaving the institution as the result of an individual project of deinstitutionalisation, with transition to independent living or some other form of care in the community is completely absent from any formal piece of regulation.

This is revealing of two essential features of the landscape of residential care services offered to persons with disabilities in Portugal. On the one hand, institutionalisation is considered as a life project, with no investment in the development of individual plans targeting transition to the community. On the other hand, this also shows the fragmented nature of the landscape of services provided to persons with disabilities, with no transition across different types of services. In both cases, the result is the same – residents of institutions, once admitted, are not easily able to leave them to live elsewhere.

This section of the report finishes with a summary table of features of visited institutions as a result of the observation grid used by the expert.

Table 3. Summary of characteristics of spaces of sampled institutions (according to checklist of spaces)

Response to items observed: **Classification of each dimension of analysis of spaces:**

🔴 No 🟡 Partially 🟢 Yes 👎 Most items below standards 👉 Some aspects need improvement 👍 Up to standards in most items

		Fieldwork visits in 2020							Fieldwork visits in 2021			
		North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North
LOCATION AND EXTERIOR	**Institution's address facilitates access and integration in the community**	👎	👍	👎	👉	👉	👍	👎	👍	👍	👎	👍
	It is centrally located relative to the village/city	🔴	🟡	🟡	🟡	🟢	🟢	🔴	🟢	🟢	🔴	🟢
	It is served by public transportation	🔴	🟢	🔴	🟢	🟢	🟢	🔴	🟢	🟢	🔴	🟢
	The public space around it facilitates circulation of pedestrians	🟡	🟢	🟡	🟡	🟢	🟡	🔴	🟢	🟢	🔴	🟡
	The location is accessible for persons with disabilities	🟡	🟢	🔴	🟢	🔴	🟢	🟢	🟢	🟢	🟡	🟢
	Building exterior is clean and well-maintained	👍	👍	👍	👍	👎	👍	👍	👍	👉	👍	👍
	Area free of trash and debris	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟡	🟢	🟢
	Walls, windows, trim intact	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟡	🟡	🟢	🟡
	Exterior stairs, sidewalk in good condition	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢	🟢
	Trees, shrubs, lawn well-maintained	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢	🟢
	No graffiti on walls	🟢	🟢	🟢	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Building exterior is attractive and welcoming	👉	👎	👉	👉	👎	👉	👍	👉	👎	👉	👉
	Materials and colours used on exterior of building inviting to residents and families	🟡	🔴	🟡	🟡	🔴	🟢	🟡	🟡	🔴	🟡	🟡
	Attractive signage clearly welcomes families and visitors and directs them to the entrance	🔴	🔴	🔴	🔴	🔴	🟡	🟡	🟡	🔴	🔴	🔴
	Covered area at entry allows transition space out of the elements	🔴	🟢	🟢	🟢	🔴	🟡	🟢	🟡	🟢	🟢	🟢
	Skip bins and other unattractive items hidden from view if near entry	🟢	🟢	🟡	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Plantings, pathways, seating, and other interesting items such as a sculpture or landmark create welcoming feel at entry	🟡	🔴	🔴	🟡	🔴	🟡	🟢	🟡	🔴	🔴	🟡
	The scale of entry is intimate and non-institutional	🟡	🔴	🟡	🔴	🟡	🟡	🟢	🟡	🔴	🔴	🟡
	Building is structurally sound and environmentally safe	👍	👉	👉	👉	👉	👍	👍	👍	👍	👍	👍
	No plumbing leaks	🟢	🟢	🟡	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Roof is in good condition with no leaks	🟢	🟢	🟡	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Heating and air conditioning systems are fully functional	🟢	🔴	🟡	🔴	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Certificate of compliance with regulations in display	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢

		Fieldwork visits in 2020							Fieldwork visits in 2021			
		North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North
	Parking area is safe and convenient	👍	👍	👍	👍	👎	👍	👍	👍	👍	👍	👍
	Located near residence's entrance	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢	🟢
	Sufficient parking for staff and families	🟢	🟢	🟡	🟢	🔴	🟡	🟢	🟡	🟢	🟢	🟡
	Parking area and pathways well-lit	🟢	🟢	🟢	🟢	🔴	🟡	🟢	🟢	🟢	🟢	🟢
	Parking area safe	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟡	🟢	🟢
	Drop-off area located where residents do not have to cross in front of moving vehicles	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢	🟢	🟢	🟢
	Outdoor lighting is adequate and welcoming	👍	👉	👍	👍	👉	👉	👍	👍	👉	👍	👍
	Security lighting on building and area around	🟢	🟢	🟢	🟢	🟡	🟡	🟢	🟢	🟢	🟢	🟢
	Exterior lighting makes residence more welcoming after dark	🟢	🔴	🟢	🟢	🟡	🟡	🟢	🟢	🟡	🟢	🟢
ENTRY	**Building is accessible to persons with disabilities**	👉	👍	👉	👍	👎	👍	👍	👍	👉	👍	👍
	Building is accessible to persons with disabilities	🟡	🟢	🟡	🟢	🔴	🟢	🟢	🟢	🟡	🟢	🟢
	Entrance to residence is safe and secure	👍	👉	👉	👍	👉	👍	👍	👍	👉	👍	👉
	Clearly marked	🟡	🟡	🟡	🟡	🟡	🟢	🟢	🟢	🟡	🟢	🟢
	Has exterior lighting	🟢	🟢	🟢	🟢	🟡	🟡	🟢	🟢	🟢	🟢	🟢
	Security system controls access to centre and screens visitors via intercom, personal contact, or technology	🟢	🟡	🟡	🟢	🟡	🟢	🟢	🟢	🟡	🟢	🔴
	Pathways free of obstacle	🟢	🟢	🟢	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟢
	Reception area is well-defined and secure	👍	👉	👉	👉	👉	👍	👉	👍	👉	👍	👉
	Signage directs visitors to reception area	🟢	🔴	🔴	🟡	🟡	🟡	🟢	🟢	🔴	🟢	🟡
	Clearly defined space for reception	🟢	🔴	🔴	🟡	🟡	🟢	🟢	🟢	🔴	🟢	🟢
	Controlled access to resident's space	🟢	🟡	🟢	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🔴
	Clear view of visitors entering centre	🟢	🟡	🟡	🟡	🟡	🟢	🔴	🟢	🟢	🟢	🟡
	Serves as transition into the centre	🟢	🟢	🟡	🟡	🟡	🟢	🟢	🟢	🟢	🟢	🟡
	Look and feel of reception area welcomes residents and visitors	👉	👉	👉	👎	👉	👉	👍	👉	👉	👉	👉
	Offers space for visitors to congregate, including seating	🔴	🔴	🔴	🟡	🟡	🟢	🟢	🔴	🔴	🟢	🟡
	Reception desk accessible to persons with disabilities	🟡	🟡	🟡	🔴	🟡	🔴	🟢	🟡	🟡	🟡	🟢
	Sets a positive and friendly tone	🟢	🟢	🟡	🔴	🟡	🟡	🟢	🟡	🟡	🟡	🟡
	Reflects care philosophy through displays and décor	🟡	🟢	🟡	🔴	🟡	🟡	🟢	🟡	🟡	🟡	🟡

		Fieldwork visits in 2020							Fieldwork visits in 2021			
		North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North
CIRCULATION AND SUPPORTING SPACES	**Circulation throughout the facility is efficient and supports person-centred approach**	👉	👍	👎	👉	👉	👉	👉	👉	👉	👉	👍
	Clearly defined pathways through the centre allow residents, families and visitors to easily move through the space without passing through individual rooms and activities rooms	🟢	🟢	🟡	🟢	🟢	🟡	🟡	🟢	🟢	🟢	🟢
	Warm and welcoming, not institutional	🟡	🟢	🟡	🔴	🟡	🟡	🟡	🟡	🟡	🟡	🟡
	Hallways are clean, well-lit, and clutter-free	🟢	🟢	🟡	🟢	🟢	🟢	🟢	🟢	🟡	🟢	🟢
	Enough room to manoeuvre strollers and wheelchairs	🟢	🟢	🔴	🟢	🟡	🟡	🟢	🟢	🟡	🟢	🟢
	Signage to direct visitors through centre and to identify spaces	🟡	🟡	🔴	🟢	🟡	🟡	🟡	🟡	🟡	🟡	🟡
	Separate office space is sufficient	👍	👎	👍	👍	👉	👍	👉	👍	👉	👍	👍
	Office space provides opportunities for confidential conversations between staff and with residents and/or families	🟢	🔴	🟢	🟢	🟡	🟢	🟡	🟢	🟡	🟢	🟢
	Sufficient number of administrative offices	🟢	🔴	🟢	🟢	🟡	🟢	🟡	🟢	🟡	🟢	🟢
	Space for files, materials, office equipment	🟢	🟡	🟢	🟢	🟡	🟢	🟡	🟢	🟡	🟢	🟢
	Ambiance fosters feeling of «home like»	👉	👍	👉	👎	👍	👍	👉	👉	👉	👉	👍
	Medical icons removed from the environment	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
	Furniture that resembles furniture one would place in their own home	🟡	🟢	🟡	🔴	🟢	🟢	🟡	🟡	🟡	🟡	🟢
	Availability of small group spaces with some visual and acoustic privacy	🟡	🟡	🔴	🔴	🟡	🟡	🟡	🟡	🟡	🟡	🟢
SPACES FOR RESIDENTS	**Familiar spatial organisation like that found in a typical house/home**	👉	👉	👎	👉	👉	👉	👉	👉	👉	👉	👍
	Spaces allow residents to move freely within the household and from one room to another	🟢	🟢	🔴	🟡	🟢	🟢	🟢	🟡	🟡	🟢	🟢
	Bedrooms do not open directly into main corridors that serve as the general circulation for a “ward”	🟡	🟡	🔴	🔴	🟢	🟡	🔴	🟡	🟡	🟡	🟢
	There are opportunities for intimate or private conversations that are comfortable, designed for couples or small groups	🟡	🟡	🔴	🔴	🟡	🟡	🔴	🟡	🟡	🟡	🟢
	Shared spaces for collective activities foster engagement and interaction among residents and staff	🟡	🟢	🟡	🟢	🟡	🟢	🟡	🟡	🟢	🟡	🟢
	Access to secure and accessible outdoor spaces	🟢	🔴	🔴	🟡	🟡	🟡	🟢	🟡	🔴	🟢	🟢

		Fieldwork visits in 2020							Fieldwork visits in 2021			
		North	Azores	Centre	Madeira	Algarve	Centre	Alentejo	North	North	Centre	North
SPACES FOR RESIDENTS	**Personalized individual bedrooms**	👉	👍	👉	👎	👉	👉	👉	👎	👉	👉	👍
	Design opportunities that will support personal items, pictures, and furniture within the private space of a resident's bedroom	🟡	🟢	🟢	🔴	🟡	🟢	🟢	🔴	🟢	🟢	🟢
	Familiar spatial relationships as you would find in one's home.	🔴	🟢	🟡	🔴	🟡	🟡	🟡	🔴	🟡	🟡	🟢
	Flexibility and autonomy	👉	👉	👎	👉	👉	👉	👉	👉	👉	👉	👍
	There is an area in or adjacent to the kitchen, where food and drink is available to residents all the time.	🟡	🟢	🔴	🟢	🔴	🟡	🔴	🔴	🔴	🔴	🟢
	Heating and cooling systems are controllable and adjustable in individual bedrooms and in separate spaces.	🔴	🔴	🟡	🔴	🔴	🟡	🟡	🔴	🔴	🟢	🟢
	Toilets and sanitary facilities are designed according to resident's specific needs and disabilities to allow for an independent use	🟢	🟢	🔴	🟢	🟢	🟢	🟡	🟢	🟢	🟢	🟢
	Use of spatial references to facilitate the autonomy of residents with difficulties of orientation circulating in the facilities	🟡	🟢	🔴	🟡	🟢	🟡	🟡	🔴	🟡	🟡	🟡
	Privacy and choice	👉	👉	👎	👉	👉	👉	👉	👎	👉	👉	👍
	The resident's room is considered personal space and there are measures in place to prevent residents from wrongfully entering rooms	🟡	🟢	🟡	🟡	🟡	🟡	🟡	🟡	🟡	🟡	🟢
	There are cabinets inside rooms that are locked and only accessible to the resident	🟡	🟡	🟡	🟡	🟡	🟡	🟢	🔴	🟡	🟡	🟢
	Toilet facilities and showering are individual or for individual use next to the bedroom	🟡	🟡	🔴	🟢	🟡	🟡	🔴	🟡	🟡	🟢	🟢
	TV set available in the resident's room to allow choice of television viewing	🟡	🟢	🔴	🔴	🟢	🟢	🟡	🔴	🟡	🟡	🟢
	Lighting controlled by the resident in his/her bedroom	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🔴	🟢	🟢	🟢
	Windows in bedrooms offer safe opening/closing mechanisms and are controlled by residents	🟢	🟢	🟡	🟡	🟢	🟢	🔴	🔴	🟢	🟢	🟢

Section 3. Challenges and Opportunities in Residential Care Settings for the Fulfilment of Human Rights: some recommendations

This section of the report offers recommendations. The recommendations are directed at European, national – including regional – levels and at the sector level stakeholders, including individual organisations delivering services to persons with disabilities as well as their representative bodies. The expert retains this terminology for the specific recommendations, though some of them may be common to more than one stakeholder group. To keep the recommendations organised in a clear manner and easy to read, a simplified logic is used in addressing the individual actors. The rationale for the recommendations is explained in detail for a more comprehensive understanding of the scope and depth of the analysis. When referring to the national level, the recommendations are not only addressed at central government bodies, ministries, and national public administration, but also, when appropriate, at sub-national, regional, and local administrative units. The phrasing of the recommendations allows to distinguish the level being addressed, but the choice to merge these different levels of public administration is related to the need to foster a more integrated approach where all levels of decision-making and regulation must work together. Several of the recommendations directed at the social care sector as a whole and at its representative bodies also target the organisations providing services. Service providers, however, are deliberately picked out of the group and offered more targeted recommendations considering their prominent role in the actual organisation and delivery of support services.

The United Nations Convention on the Rights of Persons with Disabilities, which Portugal ratified from its onset, including the optional protocol, was central to this report. It guided not only the methods used but also the analysis of the findings and the rationale followed for the formulation of recommendations. This stems from a conceptualisation of the UNCRPD as an instrument of change for both individuals and society at large as intended by its original promoters. The UNCRPD is inspired by principles of non-discrimination and refers to the protection of the rights of persons with disabilities on an equal basis with others. The core values safeguarded by the UNCRPD include respect for the inherent dignity of a person, individual autonomy including the freedom to make one's own choices and stress in, Article 3, the independence of persons and their full participation and inclusion in society. Article 19 of the UNCRPD targets those living in institutional care and emphasises the right to independent living, the right to choose where and with whom to live. All these principles shaped a rights-based approach to the recommendations put forward by the expert.

Recommendations are outlined to signal gaps in how residential care services operate in what concerns their capacity to safeguard the fulfilment of the core values and rights of persons with disabilities, and therefore to signal areas of service delivery that need to be addressed and improved. When formulating her recommendations, the expert has also placed emphasis on aspects that may have the potential to pave the way for deinstitutionalisation policies and for the creation of opportunities for those currently living in institutions to successfully transition to the community. However, the expert is fully aware that transition from institutional care to community care will take time. In the meantime, institutions that offer residential care services can and should provide their services in respect of the provisions included in the UNCRPD and creating as much as possible the opportunities for residents to enjoy a fulfilling life, realising their full potential and having their rights as citizens safeguarded. Recommendations are formulated also keeping this in mind.

The recommendations included in this report address seven dimensions of valuation that are considered of high relevance for institutions providing residential care services to persons with disabilities if they are to align their practices with the principles included in the UNCRPD. Under each dimension, concrete calls for action are outlined, in a total of 70 recommendations. The recommendations are elaborated drawing on the findings gathered from the field visits to institutions and are inspired by the main gaps identified in those same institutions.

Dimension 1. **Improve overall quality of life**

The first dimension of recommendations concerns the overall quality of life of residents. This can be looked at as a sort of umbrella for all other dimensions of recommendations that the expert will put forward in the next sub-sections. At the end of the day, the main goal of institutional care facilities should be about creating environments that are conducive to a high quality of life, which in this report is addressed from the perspective of the individual rather than from a standard definition applicable to all. Drawing on the assumption that quality of life may mean different things to different individuals, improving quality of life is mostly about putting the individual at the centre. It is about the person being in control of what constitutes the aspects of his/her life.

To create the conditions for residents to live a fulfilling life, residential care services need to be operating along the lines of a person-centred model of service provision. The term, coined many decades ago in the seminal work of Carl Rogers in the late 1950s (Brooker 2003)[8], has evolved and shows in different wordings in different countries and settings. Broadly speaking person-centred care refers to a variety of approaches to helping people entitled to care services to plan and express choices about the present and the future. It also refers to enabling people to be involved in planning how the service they currently receive is organised or delivered. A person-centred model of service provision was not what the expert has observed in the visited institutions, where, although in varied degrees, the dominant approach still displays the classic characteristics associated to institutional care: block-treatment, procedural standardisation, and dissolution of personal identities.

Introducing changes in this domain is very challenging as it touches the very core of the service provision model, one that has been in place for many decades, with historical roots that have lasted across centuries and that are very enshrined in the DNA of the institutions acting as service providers for persons with disabilities. It is, even if difficult, urgent to introduce some changes that promote a person-centred care model. In fact, any project of transition to the community will require a tailored plan of action, that needs to put the individual at the centre. For that to be achieved, there are four sub-domains that the expert recommends are tackled as a matter of priority: autonomy and freedom of choice; privacy and dignity; organisation of daily life; and personal relationships and social contacts. The specific recommendations to address these domains are the following:

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[8] Brooker D. (2003). What is person-centered care in dementia? *Reviews in Clinical Gerontology*,13(3), 215–222.

Recommendations for the improvement of the overall quality of life of residents

Service providers should

1.1 promote training opportunities for their staff on what constitutes a person-centred and rights-based approach in service delivery, with a focus on distinguishing autonomy from competence, on how to promote respect for the privacy of residents and on dimensions of dignity in provision of support.

1.2 introduce some flexibility in how daily life activities are organised and work with residents to support them in structuring their day, starting with key aspects of activities of daily living. Some examples would include: i) instead of meals being served at fixed times with all residents gathering in the dining room, in pre-set places, meals can be served within a time interval, allowing residents to decide when they want to take their meals; ii) allow residents to have visitors for a meal, upon request and within reason; iii) allow residents to sit with whom they want to sit for the meal, or to have a solitary meal if that is their wish; iv) allow residents to serve their food and secure support as adequate and requested; v) negotiate bathing times with residents, accommodating as much as possible their preferences.

1.3 revise rules for visits to residents, allowing visitors at flexible hours, according to the wishes of the resident and in respect of what are reasonable visiting times. Residents should have opportunities to welcome their visitors in private. Visitors should also be offered opportunities to participate in activities of daily living of residents if that is the wish of the resident, and as much as possible considering his/her specific needs of support.

Sectoral bodies should

1.4 engage in the production of training materials, with interactive formats, including short courses using e-learning and blended-learning methods, to promote the principles of a person-centred and rights-based model of service provision.

National authorities should

1.5 work to set-up a system of promotion of good practices, including the development of codes of conduct and standards, as well as an award-system to recognise achievement of good standards in the promotion of a person-centred and rights-based model of service delivery. ISS already has produced an excellent manual of good practices for institutional care (*Manual de Boas Práticas. Um Guia para o Acolhimento Residencial das Pessoas em Situação de Deficência*), published in 2005 and funded by the European Social Fund. Now ISS needs to move to the creation of mechanisms that promote effective translation of the contents of the manual into the sector.

The European Commission should

1.6 consider the use of Structural Funds to support the setting up of training initiatives and the dissemination of good practices, codes of conduct, and an award system. These measures should be oriented to the implementation of actions related to skills and competences building targeting the implementation of a rights-based approach in service delivery and the promotion of a person-centred model of care. One example could be supporting training for Social Security inspectors and for other public stakeholders typically involved in aspects of regulation of institutional care. Another example could be training for technical staff with coordination responsibilities in the institutional care sector that will assisting the deinstitutionalisation projects of individuals currently living in institutions.

Explanatory Notes for the Specific Recommendations

Autonomy and freedom of choice

Autonomy, understood as the ability to control one’s own life and live according to one’s own preferences is an ideal that cuts across the UNCRPD, as stated in its article 3, and that therefore cannot be diminished or constrained by means of a given living arrangement, including that involved in a collective residential setting.

It is a domain for which visited institutions still have a lot to improve as it was one where more tensions where observed, starting with the tension in how residents and staff understand autonomy. If for residents, autonomy was described as the possibility of making decisions about a given situation that concerns their lives, for the staff it had to do primarily with what individuals can do without the help of a third party, therefore with functional (and cognitive) competence. Training staff (1.1), at different levels, to distinguish autonomy from competence is something the expert sees as an important issue to create a realistic basis for the autonomy of residents to be a realisation and not just an ideal. Obstacles to deinstitutionalisation of persons living in institutional start with attitudinal barriers that simply dismiss that possibility from the onset. All material adaptations that will be necessary for successful deinstitutionalisation will be more likely to develop if there is a heightened sense of their relevance and if there is strong pressure towards their development. Preparation of deinstitutionalisation projects will not be something that will involve ticking boxes in a checklist designed to assess competence. It will need to be about planning a life project and it will need to be based in a very clear understanding of what is at stake when talking about autonomy.

Acknowledging the right to autonomy, however, cannot lead to substandard service provision whereby if a resident claims the right to do what he/she wants then he/she cannot ask for support. Autonomy is about what you want and about getting the support you need to do what you want. This is the basis for living a fulfilling life. Working with staff around the concept of autonomy, including staff with coordination responsibilities and caregivers alike, will ultimately reshape the relationship between residents and caregivers as it will redefine the relationship itself as both a means and an end. Even in situations where the competence to make the best choices may be diminished, a relationship of support of autonomy is one where the caregiver supports the individual with the process of making choices. Indeed, this will be a critical aspect for transition to community-based services, which are in principle based on active participation of individuals in managing their lives and making choices. While in institutional care, it will be critical to promote the development of this competences on the side of the person with disabilities and that can only be done if staff approaches care as support in making choices.

Making choices presupposes, however, that the individual is free to choose. Freedom of choice in turn requires having viable options and control over personal support. It is not compatible with keeping residents in a condition of passive recipients of care where each is expected to adjust to the institutional care model. Freedom of choice is about being able to make decisions about one’s life and exercise control over what help is required to achieve the chosen goals. It is not about independence in terms of self-care activities that can be measured against skills to achieve high levels of performance but rather about interdependency.

The challenge for visited institutions remains that of implementing a choice-based system. This will require significant changes in professional practices to support residents in making choices based on preferences and aspirations. The goal is to promote an attitudinal change whereby service providers focus on the ways a person can be supported to maintain their independence and do what he/she wants rather than on preventing them from doing the things they want or doing things for them. There is still a lot of learning required in this domain, both on staff and on residents’ sides and the attitudinal changes required to change the philosophy of care provision will only be achieved by combining different actions, targeting more than one dimension.

One line of action that could be beneficial for the professionals working in the residential care institutions would be the production of engaging materials for the dissemination of good practices, namely based on available evidence from other countries. The Social Security Services have already taken some steps in this direction, namely with the production of manuals of procedures that are available for consultation in their website. Although the manuals are quite detailed, they are primarily designed to assist institutions setting up a residential care service and are not so much targeting training in specific domains. The same way, although guidelines are available in the published manuals, no specific actions are implemented to promote and/or incentivise the application of the principles of autonomy and freedom of choice. An important development following the existing materials published by the regulator would be the production of interactive materials, such as short videos, brochures, and online short courses, more targeted to specific topics of rights and the elements of what constitutes a person-centred model of service provision, in formats and with a language that is accessible to all, including people with different schooling levels (1.4).

This could be further complemented with setting up some system of promotion of good practices, including the development of codes of conduct and standards, that would be used both as a benchmark for service-providers and a basis to an award-system that would recognise the achievement of good standards in service provision in the light of the principles of a person-centred model of care. Such a system could be developed under the coordination of INR, the body in charge of supervising the implementation of the CRPD in Portugal (1.5).

Privacy and dignity

Privacy and dignity are arguably essential aspects of personal identity and often at odds with living arrangements of a collective nature. This is a domain where visited institutions showed some relevant gaps that require some specific attention.

Firstly, privacy and dignity involve having a personal space, materially and symbolically. Residents must have the opportunity to enjoy a personal space, where their possessions, thoughts and feelings are under the exclusive control of the resident. This must be a place where nobody else enters or uses without the permission of the resident. Residents should also be able to see others in private, both for personal and professional reasons, as well as being assured communications remain confidential and private (see more on Physical Environment).

Secondly, privacy and dignity must be always safeguarded, and they cannot be overridden by operational performance criteria. Important areas that need to be improved involve provision of intimate and personal support, expressions of intimacy and sexuality, discussions about sensitive or personal information, entering bedrooms, toilets, and bathrooms.

Thirdly, privacy and dignity are about putting the person at the centre and offering support according to needs and preferences. This involves respecting the resident’s preferences in terms of their personal appearance and addressing the resident as an adult rather than as a child.

The training (1.1 and 1.4) and the promotion of good practices (1.5) outlined above for the realisation of autonomy and freedom of choice apply as well to the promotion of dignity and privacy, both key elements of what constitutes a person-centred model of service provision.

Organisation of daily life

One of the core elements of the so-called institutional care model is the lack of meaningful control residents retain over different aspects of their lives, bound by the institutional schedule and the demands from the staff. This relates to the limited opportunities to exercise choice discussed above. The reality observed in the visited institutions shows that many residents are not able to make simple everyday choices that most people take for granted: what and when to eat; who to socialize with; what TV program to watch; whether to go out or not, whether to engage in some leisure activity or not.

For the implementation of a truly person-centred model of service provision, group routines must give room to the individual working out, with support if needed and requested, a structure to his/her daily life, one that reflects as much as possible his/her goals, expectations, and needs. This means moving away from a standardised organisation of routines to introduce the necessary flexibility to account for differences among residents. The expert acknowledges that in a collective setting there must be some predictability and planning, but not to the point of diluting the participation of the individual in the organisation of his/her day. The need to have some scheduling is not necessarily incompatible with residents retaining some control over the timing of their bathing or their meals. Rather than the classic boarding school approach to the organisation of daily activities, service providers should create opportunities for residents to engage in meaningful social interactions in activities of daily living, including mealtimes. Activities of daily life such as preparing the meal and the meal space, serving one's food to one's plate according to how hungry one is feeling, choosing with whom to sit for the meal or choosing to be alone for the meal, are important aspects of control that most residents in visited institutions are deprived of. This further extends to other aspects of daily life: bathing time, wake-up and sleeping time; time to watch TV; what TV channel is on. In a nutshell, service provision follows a set menu approach with little to no room for alternatives and those alternatives must be created (1.2). This does not come without some additional needs for allocation of resources, especially human resources. Although staff-specific needs are addressed in a dedicated dimension of recommendations, it is important to acknowledge that implementing a truly person-centred model of service provision is likely to require, for most institutions, an increase in the number of workers, especially caregivers. It will also require, in many cases, rethinking the layout of spaces as they are typically prepared for communal life according to standardised sets of routines.

Personal relationships and social contacts

Being in institutional care cannot mean cutting off ties with the outside world and being confined to the social networks created inside the institution. Although these are important in themselves, residents must be supported and encouraged to maintain personal relationships according to their wishes, including with groups in the community, with relatives, friends, and significant people as well as former relationships that existed prior to admission in the residence. This is a domain in which visited institutions have not invested sufficiently and where there is room for improvement. In fact, when planning for transition to the community, an important resource individuals will need to activate is the network of relationships with significant others. Not promoting the growth of these networks is in itself an obstacle to deinstitutionalisation.

Residents must be able to see and talk to whoever they want, when they want, within reason, and with appropriate protective measures and support as adequate. This includes receiving visitors in private, at flexible hours, within reasonable arrangements; having access to communication channels such as phone, email, social media, and other information means as adequate; having access to cultural life, sports, and leisure activities outside the institution (1.3). These are all aspects that are underdeveloped in visited institutions and that raise some concerns. They are certainly related to some aspects that are not exclusively controlled by institutions, some of those to be discussed in more detail in subsequent recommendations. For example, participating in activities outside the institution will only be possible if the outside environments are inclusive and prepared for the participation of all irrespective of their specific characteristics and needs. And this is something that is not just the responsibility of institutions but rather something that involves society. It is in any case a very critical aspect that will pave the way for successful deinstitutionalisation projects. The ultimate purpose of deinstitutionalisation is full inclusion in the community. The ties need to start being built even before the individual leaves the institution and therefore the importance of fostering connection to the outside of the institution.

Overall, and as stated in the opening of the first group of recommendations, the challenge is to guarantee that life at the institutional care facility is lived in a fulfilling manner, considering the life project the resident wants to be his/hers. That is what quality of life is primarily about. To get there, several other specific dimensions need to be addressed. Those are addressed in the next sections.

Dimension 2. **Address needs of staff working at residential care institutions**

The second dimension of recommendations is focused on the staff working at the visited institutions. Although the expert will mention the staff, and in particular training of staff, across several other dimensions of recommendations (which is inevitable given how all things are intertwined), this dimension focus on more specific aspects that relate to how institutions organise and manage their human resources.

Staff is a key component of the service delivery and has a major impact in how a resident lives his/her daily life and in the quality of that life. Staff working at residential care institutions includes different groups of professionals, from the general management and the technical staff with coordination responsibilities, to the caregivers that interact with residents and support them in daily life activities and the staff in charge of the complementary operations (e.g. cleaning, preparing meals, laundry, and transportation).

For all professionals a fine balance of adequate knowledge and skills with qualities and attitudes is required, topped with a good dose of enthusiasm and motivation as well. Reaching this fine balance should be embraced by the visited institutions as a top priority since in all, *albeit* with variations, it was evident how unresolved problems at the staff level were impacting the service delivery and hampering some critical dimensions of rights of the residents, as discussed in section 2 of this report. The problems observed were amplified in the group of caregivers, those working directly with residents, but most of the recommendations outlined in the following paragraphs are applicable, with adaptations, to all groups of staff.

Recommendations are organised into three sub-dimensions: recruitment, training and working conditions and monitoring.

Recommendations for the improvement of performance of staff working in institutions

Service providers should	
2.1	outline the competencies and personal attributes desired for prospective workers, to have a reference against which candidates fit is assessed and to assist coordinators in the elaboration of integration plans of new hires.
2.2	assess the representations and understandings of disability among staff against a framework of rights and based on the principles contained in the UNCRPD. The results of such an assessment should then be used as a starting point for the preparation of training and integration strategies of staff.
2.3	prepare integration and training programs, assisted by staff, to help new workers integrate in the institution and adjusting these programs to the principles of a person-centred and rights-based approach to service delivery.
2.4	create opportunities for residents to participate in the definition of skills and competences of staff, in the elaboration of job descriptions and in the integration of new workers.
2.5	promote staff retention by revising working schedules and shifts, introducing some stability in working arrangements and facilitating as much as possible conciliation of work and family life, especially among the caregivers group.
2.6	promote closer collaboration between coordinating staff and caregivers, towards a more horizontal model of organisation of work that helps overcoming tensions associated to the perception of caregivers as lower-level workers.

Recommendations for the improvement of performance of staff working in institutions (cont.)

Service providers should (cont.)

2.7 promote engagement of staff by resorting to some organisational branding strategies. This can be achieved by working on the establishment of the philosophy of service provision, involving the staff together with residents in the elaboration of that statement and using it as an element of team spirit building.

Sectoral bodies should

2.8 promote training of staff working in residential care institutions, including all levels of staff, as a continuous process keeping a constant offer of training in key domains of rights of persons with disabilities. In preparing these training programs and respective materials, they should consult with organisations representing the rights of persons with disabilities and with the academia.

2.9 promote skills formation among managers and coordinating staff in the field of human resources management in articulation with the promotion of a rights-based approach to service delivery.

National authorities should

2.10 raise the profile of training in the residential care services sector by means of funding of training initiatives and by directly engaging in the organisation of training programs, working with the academia and with organisations representing the rights of persons with disabilities.

2.11 include training of staff working in residential care services in domains of rights in the list of activities to be implemented under the National Strategy for the Inclusion of Persons with Disabilities 2021-2025.

2.12 revise the use of a standard threshold for the number of staff needed and introduce a nuanced approach that considers the needs of residents, the size, the layout, and the type of services that the service provider offers and adjust payment rates accordingly.

Explanatory Notes for the Specific Recommendations

Recruitment

The biggest difficulty visited institutions experience in terms of recruitment involves the recruitment of caregivers. Care professions in Portugal, as elsewhere, have been historically less valued than other professions. The history of care professions is an intricate history of gendered divisions of labour and naturalisation of functions of care. It is largely the type of work seen as something anyone can do, especially if that someone is a woman. It is the type of work that comes with a low salary but with heavy work and demanding working schedules, typically working in shifts and often long hours and during the night. All these together turn the job not attractive on the labour force side. On the demand side, service providers tend to feel they have to settle with whoever shows up since the number of candidates is usually low, and because they themselves largely believe anyone can do the job. The result is not only the difficulty in recruiting, but also the recruitment of poorly qualified workers that not only lack the technical skills required to act as a caregiver but also, often, the personal attributes (e.g. understandings of disability; ability to interact and relate to others, just to mention a few).

The implementation of a person-centred model of service provision based on rights requires the careful identification of competencies and personal attributes the staff should possess (2.1). This holds not only for caregivers but for all categories of staff working in the residential care institution. The obvious objection to this, as phrased by the managers of institutions, is that the shortage of candidates for the post of caregiver is such that if the selection criteria are too strict there is the risk of hiring nobody. The risk is there, in fact, and only a broad systemic change that deals with the root of the problem would eliminate the risk. However, even in a scenario of shortage of candidates, having a clear identification of competencies and personal attributes for the staff to hire will offer a reference, a benchmark against which candidates' fit will be assessed to help design training programs and plans of integration in the institution. Even if the fit is not entirely there, measuring the distance between the expected competencies and attributes and what the candidate offers helps assess whether the person will be capable of building a meaningful relationship with residents and how the worker will have to be assisted to achieve the desired outcomes.

Another aspect of recruitment often forgotten concerns the general attitudes and social representations about disability. Candidates to any post in the residential care institution, as any regular citizen, will carry a lot of baggage in what concerns representations and understandings of disability. These representations will certainly impact the way they will perform their roles as professionals and will ultimately impact the relationship they will build with residents. These representations are collectively shared and part of the socialisation of everyone as member of a community, in this case the Portuguese population and culture. Service providers certainly cannot change the culture of the country but acknowledging that potential workers may not be tuned in with the principles outlined in the UNCRPD is a good starting point to prepare some training and integration strategies (2.2 and 2.3). For example, before taking-up the post, all staff should be offered a written job description with a detailed description of terms and conditions of the post for which he/she is being hired. This goes beyond the formal contractual conditions and includes a statement about the philosophy of care that the institution wants to promote, about the type of relationship the staff is expected to have with residents. Similarly, when recruiting new workers, institutions should carefully prepare integration and training programs, tailored to the competences and attributes of the new worker, and designed to help him/her adjust to the principles of a person-centred model of care provision and to the promotion and safeguard of the rights of residents. Caregivers cannot continue to be thrown to the task without any formal integration and training, as it is the current situation in most of the visited institutions.

Finally, residents should be given the opportunity to participate, to the best of their ability, in the definition of skills and expertise of staff to be hired, to contribute to the job description and be active participants in the integration and training of new hires (2.4). This does not necessarily involve thinking of a stand-alone specific activity. It can be part of a broader process of collecting feedback from residents about their experiences with the staff and using the feedback to identify unmet needs and the goodness-of-fit of staff's attitudes and performance against the expectations and evaluations from residents. It can also be achieved by engaging residents in the training and integration program of new staff members (e.g. asking a resident to explain how things operate in the facilities; organising meetings of residents with caregivers to share views and opinions about how the facilities are running).

Training

Training is an important line of action not only when a worker is hired for the first time to work in the institution, but also as part of an evolving path of improvement. This applies to staff at all levels. To overcome some of the limitations of the current model of service provision found in the visited institutions it will be essential to operate some changes in how staff understands the job of caregiving and of coordinating caregiving activities – it will be necessary to move from an understanding of caregiving that emphasises dealing with bodies to meet their basic needs, to one that sees caregiving primarily as engaging in support relationships that create opportunities for the residents to achieve the highest quality of life possible. This is an area of investment that will have direct impacts not only in the quality of life of those currently living in institutions but will also qualify an important share of the labour force of the sector that will be potentially pooled into community-based services as these expand and as the institutional care sector decreases in size. Community-based support services require a set of skills from professionals that are currently quite different from what one finds among staff working in institutions. When addressing transition of persons with disabilities from institutions to the community, one can and probably should also think about transition of professionals.

Some of the most pressing areas of training that are missing include communication with persons with disabilities and understanding the rights of individuals to autonomy, freedom of choice, privacy, and dignity. Training programs for the residential care sector are certainly needed but the offer available is close to none, both by initiative of institutions and offered by third parties. This can be better organised at the sector level and a project that representative bodies and NGOs representing the rights of persons with disabilities should lead (2.8 and 2.10). It is an area where the regulator should also take responsibility, both by means of funding and by means of direct involvement in the organisation of training programs. It is an area where the use of European Funds should be considered given the underdevelopment of the existing offer and the dimension of the universe of workers that are to be targeted. It should be noted that the Strategy for the Inclusion of Persons with Disabilities for 2021-2025, and although training of agents involved in several sectors ranks high in the list of priorities, does not include any specific mention or activity of training of staff in residential care institutions in areas related to rights and person-centred models of care provision (2.11). The topic that is singled out in the strategy for training is prevention of abuse and violence. Although it is intolerable the thought of staff abusing or being violent towards residents, the truth is that it is the type of behaviour that has deep roots and is often associated to poor working conditions and lack of training to do the job. Singling out the issue of abuse without addressing the broader context of work where these episodes take place may be of limited impact.

Training, however, is not something that takes place exclusively within the scope of a formal program. It is something that service providers should address as part of the continuous process of improvement of one's professional practices. In that sense, it is essential that the management and those with coordination responsibilities hear the staff, especially caregivers, involve them in the assessment of needs of residents and in the monitoring of the quality of life of residents. If residents cannot be considered as passive recipients of the care delivered by caregivers, caregivers cannot be managed as passive executors of tasks. Training caregivers to engage in meaningful relationships of support with residents also involves considering them as active agents in that relationship and valuing them as workers.

Working conditions and engagement of staff

The third aspect the expert wants to highlight concerns much needed actions for the improvement of the working conditions of the staff and in the mechanisms of monitoring of performance and engagement of workers. The continuity of support and the maintenance of relationships between the staff and the residents is a critical aspect that impacts the quality of life of all those living in institutions. The high rotation of staff, especially among caregivers, observed in the visited institutions is very detrimental to the lives of residents and very cost-ineffective for the service providers.

To improve the current situation, it is important to act urgently in two different, although complementary, aspects: increasing the number of workers and implementing retention strategies.

In almost all the visited institutions, except for the one where the level of independence of all residents in activities of daily living was very high, there was a clear shortage of staff in the caregivers' group, made worse by the high levels of absenteeism observed in most settings. This often leads to temporary placements of workers and most of the times to an excessive workload on those present at work.

The number of staff needed in a residential care institution cannot be defined against a standard threshold that the regulator uses to estimate the structure of costs of delivery of services, but rather needs to be defined according to the needs of support of residents, taking into consideration the size, the layout and the services provided by the residential care unit (2.12). On the regulator's side the preference has been for a standardised approach to the rules applicable to service providers in the social care services. This also includes dispositions about staff. The promotion of a rights-based person-centred model of service provision requires a more flexible standpoint, including in the definition of the number of caregivers needed in each institution. Personal plans need to be implemented and this is what should determine the staff that needs to be present in the residential care facility at any given time. Cost calculations need to be adjusted accordingly so that funds transferred from the State to service providers reflect their real needs and structure of costs.

According to regulations in place, the minimum number of caregivers an institution needs to include in its list of personnel to be licensed to operate is 1 caregiver for each 3 residents. And this rule applies generally. If we do a simulation and we analyse it against the evidence collected during the visits, it will be clear the mismatch between the minimum ratio defined by the regulator and the reality of some institutions. For example, in an institution with residents who have very high levels of dependence, with 70 residents distributed across 2 residential units, the number of caregivers would be 24, probably 12 in each unit of 35 residents. Work must be secured 24/7, which typically involves two dayshifts and one nightshift. If one considers the minimum of 2 staff members on site, at night, as the very minimum to guarantee the safety of residents, that leaves 10 staff members to secure the two dayshifts, which would roughly mean a ratio, on site, of 1 caregiver for each 7 residents. And all this not considering that workers do not work seven days a week but rather five, and that there are always workers missing for a myriad of reasons. In a nutshell, for some of the visited institutions this is clearly insufficient and can only work if methods of work are implemented to maximise productivity of workers, most of the times sacrificing the quality of care the resident will receive.

It is equally important to promote active strategies of engagement and commitment of the staff to increase the chances of retaining workers. This will not only impact the quality of life of residents, but it will also be cost-effective to service providers as recruitment and integration are, themselves, costly and time-consuming.

One aspect of improvement of working conditions that will improve the levels of satisfaction of caregivers and increase the likelihood of the worker staying at the institution concerns the organisation of working hours (2.5). Stability of arrangements and conciliation of working hours with family life are areas where the management needs to find ways to improve.

Engagement and commitment also involve organising regular assessments of competences of staff, to guarantee workers retain competences in key domains and counteract the tendency for the staff to become institutionalised themselves. This is an area that needs to be improved and staff with coordination responsibilities needs to engage more actively with caregivers and monitor in a participatory manner work and performance. Relationships among staff in visited institutions are overly verticalized, very much along the lines of the model of organisation of work one finds in the state bureaucracy. Workers need to feel valued and particular attention must be paid to caregivers, that cannot be considered as lower-level workers (2.6).

Engagement and commitment are also achieved by making it clear to all to what they are committing. Service providers would benefit from defining and stating a philosophy of care that would brand the institution (2.7). In doing so, they should involve all staff members, and residents alike, in the definition of what type of institution they want theirs to be. From this a code of conduct for the staff should be developed, one in which all would participate to formulate it and for which all would be accountable for.

Although ideally these are developments one would prefer to see as the result of the initiative of service providers, sectoral bodies and the regulator do have an important role to help trigger changes (2.9). A good place to start is skills formation, namely targeting those with management responsibilities that often lack competences in human resources management. Alliances with NGO's representing the rights of persons with disabilities and with the academia are probably the easiest path to move forward on this front. The use of European Funds to support these training actions is also something that should be considered.

Dimension 3. Approach safeguarding and protection as dimensions of empowerment

In the third dimension of recommendations for improvement, the expert would like to address two issues that gained relevance after visiting the selected institutions and collecting testimonies from residents, families, and some staff as well. These are issues relatively well addressed by the regulations in place. However, the observation of the reality raised enough evidence to support the claim for some additional and continuing effort of clarification and improvement. The first of those issues concerns the right of residents to feel safe, not only from abuse or neglect, but also about the stability of their living arrangements to avoid what was perceived at times as a forced conformity based on fear of retaliation, among both residents and their relatives. The second issue concerns the need for protection measures to be addressed within a more global approach to the management of risks, especially to avoid exacerbated representations of vulnerability that end up depriving residents of opportunities to live their lives in a fulfilling manner. In the explanatory notes, the expert addresses each of these issues separately for clarity purposes, although in practice they are strongly correlated. These issues, as the expert will discuss in this section, are also considered fundamental in terms of capacity building in preparation for transition to community-based living arrangements. Years living in an institution breeds an institutional mindset on the residents' side, disempowering them in critical dimensions of life that will be essential if they are to pursue a life project included in the community. Activation of those dimensions will be fundamental to ground a deinstitutionalisation approach.

Recommendations for the improvement of safeguarding and protection of residents

Service providers should	
3.1	work with residents and their families on their rights, to raise awareness for the subject and as part of their personal development, rather than focusing exclusively on the issuing of statements on rights that have a very limited reach and are often unknown to the individuals concerned.
3.2	work with NGO's representing the rights of persons with disabilities to open permanent channels of communication between residents and independent third parties, including support mechanisms to those hampered in their capacity to communicate, so that residents can raise any issue they consider may be limiting their rights or they perceive as abuse and/or neglect.
3.3	always have enough staff on site to guarantee adequate levels of service delivery and permanent supervision of quality of support.
3.4	train staff on prevention and detection of abuse.
3.5	include financial management in the personal development plan of each resident and work towards empowering residents to be in control, to the best of their ability, of their finances, not only to train for autonomy but also to prevent financial abuse.
3.6	train staff to respond to problematic behaviour and work when needed with professionals with expertise in the subject.
3.7	support responsible risk taking by residents rather than a model of service delivery purely based on risk avoidance. For example: guarantee access to the Internet to all residents; create dedicated spaces where residents can prepare, with support as needed and requested, food and drinks; support residents to be able to go in and out of the institution rather than assuming that going out is always a risk to be avoided.

National authorities should (cont.)	
3.8	work with NGO's representing the rights of persons with disabilities to facilitate their work as advocates and advocacy services independent from institutions and establish concrete plans of action to make these services available to residents in institutions.
3.9	revise protocols concerning the management of problematic behaviour of residents and elaborate guidelines and gold standards to guide service providers and their staff.
3.10	engage in the creation of inclusive environments that facilitate safe participation of residents in the community.

Explanatory Notes for the Specific Recommendations

Safeguarding

There are clear regulations in place concerning abuse and neglect, with a complete legislative framework. The topic undoubtedly still has relevance since it shows in the national strategy for 2021-2025 as one of the priorities for the sector of residential care services. The fieldwork conducted by the expert did not raise concerns at a systemic level, and although episodes of abuse or neglect as defined in the Portuguese legislation were identified, these were clearly isolated episodes. The fact they are isolated episodes does not diminish their relevance, but they are to be addressed from a different angle relative to what the expert wishes to emphasise in her recommendations. The issue that the expert wants to raise concerns the measures in place to guarantee that individuals retain some autonomy to safeguard their rights. The assumption is that safeguarding rights must also involve a pro-active approach from the bearer of rights, that is empowered to recognise his/her rights and to demand his/her rights are respected.

The procedures in place in all visited institutions do not offer any opportunity for residents to have access to an advocate or an advocacy service independent from the institution. Quite on the contrary, when some event considered out of the ordinary takes place, the protocol is to fill in a record of occurrences. This record is filled in by the staff and later analysed by those with coordination responsibilities, and in the most serious cases by the director of the residential care facility. There is an absence of balances and checks that safeguards residents' interests. They are, for all matters, in a position where the distribution of power is very unbalanced, to the disadvantage of residents. This is often the reason for the apparent conformity and acceptance on the residents' side, and their relatives, towards circumstances that objectively are not to their liking, and in some cases may even be perceived as abusive. Fear of consequences if expressing disagreement and/or complaining is still a reality, whether grounded in facts or not, but as such perceived and so equally relevant in terms of impacts in the lives of residents.

On this front many and varied things can be done to improve the current situation.

On the one hand it is important to work with residents on their rights, as some institutions are starting to do (3.1). The work must go deeper and be part of a support approach aiming at empowering individuals to become active agents in safeguarding their own rights. To start, this involves raising awareness among residents about their rights, an issue that remains largely unknown for many of those living in the visited institutions. In fact, this is something that should be also integrated in the IPs with the definition of concrete activities, targets to be achieved and measurable indicators of achievement.

On the other hand, residents must have available forms of communication with third parties, independent from the institution, if they want to raise any issue concerning any perceived form of abuse or neglect that they may consider they are suffering (3.2. and 3.8). At present, staff from the residence and relatives are the only persons that residents can contact. This becomes even more so for those who are hampered in their capacity to communicate autonomously. Support must be provided to these individuals in accessing forms of communication with third parties (see more below on rights under dimension 5).

It is equally important to work with the staff. First, this goes back to the importance of always having the necessary number of staff on-site (3.3). Understaffing, especially in the night shift, puts residents at risk if some event out of the ordinary takes place. Understaffing also increases the likelihood of burnout among caregivers, which is in turn associated to a higher risk of abuse and neglect. Absence of appropriate supervision was observed in the visited institutions, especially on weekends, which translates into a lower quality of the service delivered to residents.

Working with staff should also be done by means of training on specific domains, among which the expert would highlight prevention and detection of abuse; how to report abuse; what constitutes abuse in an institutional setting; and strategies to address the vulnerability of persons with disabilities to abuse, especially those with communication impairments (3.4). Going back to what was stated on the recommendations for the staff under dimension 2, this should be integrated in a broader training programme on working with persons with disabilities from a person-centred approach.

An even more specific topic concerns the prevention of financial abuse (3.5). As a principle, each resident should exercise control over personal finances, if that is what he/she wishes and considering availability of support when needed. This is not the reality of most residents in visited institutions. For most of them it is either the institution or a relative that controls the personal finances, even if some accounting mechanisms are informally implemented by the management. Not controlling one's finances and not deciding on how to spend available funds can be considered a form of abuse as a third party is disposing of financial resources that are, for all purposes, the property of the resident.

Access to information and advice and support on financial management is a domain of development that should be approached by institutions in a more structured manner and included in IPs wherever appropriate and to the best of the individual's ability. This would lay the basis for residents to be able to retain control of their own money and spend it according to their wishes. In those cases where the resident requires assistance to manage his/her financials, a person should be appointed to help, by him/her or by an independent body. But, as a principle, it should not be a staff member or a representative of the service provider to take that role as that constitutes a fundamental conflict of interests. In fact, money of the resident should not be used to pay for any expenses or added to any common fund without prior knowledge and authorisation of either the resident or the person that is chosen to support him/her on issues of decision-making (see more on rights under dimension 5). The capacity building that is involved in these recommendations is essential as well when planning for a desinstitusionalisation approach, as the skills discussed are fundamental to an empowered participation in the community.

Protection: managing risks and behaviour

Side by side with the safeguarding of residents to protect them from neglect and abuse, comes the need to manage the risks of residents' behaviour, the risks to themselves and to others. This topic was overly emphasised by caregivers and is one of the main sources of problems and tensions in their work.

Priority must be given to training staff to understand and respond positively to problematic behaviour (3.6). For that to be successful it is important to define protocols and gold standards to guide organisations (3.9). For example, defining in what circumstances is resorting to a restrictive measure acceptable. Spatial restriction and removal of objects and personal belongings as a form of punishment is used more often than it should and cannot be part of a standard approach to managing problematic behaviour.

In those cases where the problematic behaviour of the resident continues, professional assessment may be required and a specific plan to manage problematic behaviour may need to be defined. Including the resident, relatives, and caregivers in the process of elaboration of the plan of management of problematic behaviour is a key component of what should remain a person-centred approach. What cannot happen is a reactive approach from the staff and from other residents that resort to slapping or punishments like losing privileges to use the computer, the mobile phone, or being sent to the bedroom for some time-out.

Risk management, however, is often exacerbated and ends up being quite harmful to the opportunities residents are offered to realise their full potential and live fulfilling lives. It is one of those paradoxical aspects that must be acknowledged. The challenge is that of embracing risk management as a domain of development.

The model of service delivery observed in the majority of visited institutions is invariably understood as being at the service of guaranteeing the safety of residents. This comes embedded in a culture of risk avoidance anchored in a generalised understanding of disability as being a condition of risk for the resident. This is the attitudinal basis of what ends up being a rather disempowering model of service provision.

Risk management should support responsible risk taking rather than plain and simple avoidance of any risks, if one considers that taking risks is part of normal life. From that perspective, supporting residents in responsible risk taking, according to their specific characteristics, needs and preferences, becomes a means of improving individual quality of life, skills, and abilities (3.7). When considering transition to community-based living arrangements this is a domain of life that will not be possible to avoid and once again it is critical individuals are empowered to manage risks in their daily lives. Based on the observations collected from the visited institutions, there are some practical aspects of service delivery that should be revised in view of this principle.

All residents should have access to the Internet as it is today an extremely important means of social connectedness and access to information with great potential for participation. Risks associated to online presence and contents can be managed, namely supporting individuals in managing those risks themselves, but cannot be used as a justification for depriving residents of access to the Internet and its functionalities.

Residents should also be given opportunities to participate in activities of daily living to the best of one's abilities and supported in the recognition and control of risks associated to those activities. The fact that devices are plugged to the electricity or that some products are hazardous poses some risks but using those risks as a justification for keeping individuals distant from what would otherwise be components of a normal life is disempowering. This may require revision of some regulations in place, namely those that apply to areas such as kitchens, laundry rooms and storage areas in institutional settings.

An activity of particular relevance is that associated to the preparation of food. The size of many of the residences involves the preparation of meals in industrial kitchens that are not adequate for the involvement of residents, not because they have some disability but because, like any other ordinary citizen, they lack the technical skills to operate the devices one finds in those spaces. An option would be to have alternative dedicated spaces where residents could, to the best of their abilities, prepare food to their liking and retain some control over such a basic aspect of daily life. This would also be an important aspect of training for autonomy in preparation for deinstitutionalisation.

Going in and out of the residence was signalled as a difficult topic for most institutions. The main argument that is discursively used goes back to risk avoidance and a heightened sense of vulnerability of residents. As a principle, although subject to individual assessments, residents should be able to go in and out if the staff is informed about the whereabouts of the individual. One practical example mentioned by many of the interviewed residents as one of the most desired activities is the possibility of going out for a meal in a restaurant. This would be for many a reasonable target in terms of personal development and one that could be part of a supportive approach to risk management.

All these however must be integrated in a broader framework, one that promotes a holistic approach to disability (3.10). If the residence is located far from the community, with no available public transportation; if there are no sidewalks where individuals can safely walk or drive their wheelchairs; if urban planning still does not guarantee that all places are inclusive; then what was suggested in the previous paragraphs becomes an empty rhetoric.

Dimension 4. Improve approaches to personal development and healthcare

Person-centred models of service delivery in residential care institutions are about organising for the delivery of services making sure they put the individual at the centre and that they promote personal development in all aspects of life. In the process of doing so, individual development plans are an important tool to sustain a person-centred approach and all institutions use them as defined in the regulations for the sector. How they use them, and the gaps found in some dimensions of personal development and individual rights though suggest there is still room for improvement. In the following sections the expert offers some recommendations for both the procedural aspects and some areas of personal development, including access to healthcare and self-care, in the light of a human-rights approach to personal development.

Recommendations for the improvement of personal development and health of residents

Service providers should	
4.1	shift from a capacity-based approach to personal development to a model of needs assessment and promotion of abilities.
4.2	nominate one caregiver per resident to engage in the personal development plan of the respective resident together with them, as part of promoting a relationship of proximity.
4.3	support residents to be proactive in the pursuit of a good health condition and to take responsibility for their health. Preventive healthcare should be included in personal plans of development.
4.4	integrate education, training, and opportunities to integrate the labour market as key components of the life project outlined in the personal development plan of residents, based on their wishes.
4.5	**together with sectoral bodies and national authorities should** collaborate and increase the investment of effort and resources in campaigning and awareness raising to positively influence the attitudes of the population towards disability.
Sector bodies and NGO's representing the rights of persons with disabilities should	
4.6	promote the consideration of leisure, sports, and culture as dimensions of social participation in the community instead of as purely occupational activities.
National authorities should	
4.7	consider making the inclusion of a plan of deinstitutionalisation mandatory in the elaboration and subsequent revisions of personal development plans of residents.
4.8	promote holistic approaches to the personal development of residents in institutions rather than focusing on provision of care to satisfy basic needs.

National authorities should (cont.)	
4.9	look at topping up the disability cash benefits each resident receives with personal budgets for healthcare considering their specific needs and their personal development plans.
4.10	strengthen the opportunities for integrated healthcare, specifically in what concerns residents with multimorbidity and mental health problems. Stronger articulation of institutions with healthcare professionals in mental health is required.
4.11	promote the reduction of physical, financial, and symbolic distances between institutions and the places where leisure, sports and cultural activities in the community take place.
4.12	consider personal budgets for sports, leisure, and cultural activities of residents currently residing in institutions, considering their personal plans of development, and based on principles of equity in access to those activities.
The European Commission should	
4.13	consider funding projects promoting adaptations in sports, leisure and cultural infrastructures of local communities that target facilitating participation - and access to community-based services - of those currently living in institutions.

Explanatory Notes for the Specific Recommendations

Personal development

Having a regulatory framework that mandates all institutions to keep individual plans of care is not a guarantee that those plans are effective in promoting personal development. This is related to two main aspects that would benefit from improvement. Firstly, if individual plans are designed within a culture of care that does not promote a person-centred model of service delivery, they end up being one more form, an administrative procedure carried out to satisfy the regulator but that, in practical terms, have limited implications for the opportunities residents have for personal development. Secondly, there are no mechanisms in place to secure independent assessments of performance of institutions against set targets for personal development. In the next paragraphs, the expert dwells a bit into these two aspects.

If one looks at the template that the regulator offers for the elaboration of individual development plans, there is a diagnostics component still very influenced by the biomedical approach to disability, focused mostly on measuring capacities and primarily in the domains that constitute the activities of daily living (bathing, dressing, going in and out of bed, eating, etc.). The diagnostics also includes the identification of habits and interests of the resident prior to admission in several dimensions of life, ranging from personal relationships and social networks to leisure activities, daily activities and routines, religious activities, among others[9]. There is also room for a diagnostic of interests and expectations in terms of future personal development. The diagnostics is expected to be done involving the prospective resident and his/her relatives as well as any other social actors deemed relevant for the process. The result is expected to ground the elaboration of the individual development plan. For that part there is also a recommended template that guides institutions in terms of the areas of development they should consider. The approach is influenced by Schallock's Quality Framework (Wang et al., 2010)[10]. The dimensions of personal development institutions are recommended to consider include personal

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[9] To see the full template recommended by the regulatory bodies to residential care institutions for people with disabilities see the Guide on Key Processes (*Manual de Processos-Chave*) at http://www.seg-social.pt/documents/10152/13454/gqrs_lar_residencial_processos-Chave/f1f50be0-d188-4016-8a5c-25cf3191da6a.

[10] Wang, M., Schalock, R.L., Verdugo, M.A. & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities*, 115, 218–233, p.221.

relationships, self-determination, emotional, physical, and material well-being, employability/occupation of time, citizenship, and rights.

Overall, and just based on face-value, one would assume the model in place is adequate to promote a person-centred service delivery focused on personal development. That does not seem to be the case however, at least not for most visited institutions, and this due to the *de facto* use of personal plans (4.1).

To start with, staff in charge of elaborating the personal plans is still primarily focused on measuring capacities rather than on maintaining functional abilities. The difference between measuring capacities and functional abilities is that the first looks at what the individual can do in each environment considering his/her intrinsic characteristics. Functional abilities are about identifying the necessary adaptations in the environment so that individuals can do what they want. The dominant attitude is still focused on intrinsic capacities. This means, among other things, that some areas of development are to exclude as the individual is labelled not capable. This, on the other hand, is also related to the way personal projects are defined. They tend to be bounded by the type of services and facilities available on the side of the service provider, with little room for a real fitting of responses to the individual's preferences and needs if the match is not there by default. Thirdly, it should really involve all stakeholders (residents, relatives, caregivers, and other relevant agents) and not be elaborated by the staff with coordinating responsibilities and then validated by relatives and, when possible, by residents. Fourthly, personal development plans must really operate as personal projects and therefore should be kept by the individual. Currently, they are managed as a form stored in the file of the resident for administrative purposes.

Personal development plans are dynamic, which means they need to be monitored and revised as often as necessary. Although a routine of assessment and revision is defined by the regulator, in practice institutions are doing it on a yearly basis and roughly the same way one would expect to see if it were a school issuing grades. This requires some changes as well, both attitudinal and procedural. Monitoring personal development plans is not about grading success in achieving goals but rather about finding the best responses to the needs and preferences of residents, which evolve and change over time. In fact, the foundations of deinstitutionalisation approaches to those currently living in institutions will have to be laid down here. Investment on training and capacity building on this topic will be fundamental not only to improve quality of life of residents in the short term, but to pave the way for a successful implementation of deinstitutionalisation protocols.

Personal development plans are, as the name itself suggests, personal and therefore need to be implemented and monitored within a relationship of proximity (4.2). Rather than a clear cut of responsibilities between caregivers and coordinating staff, by which only the coordinators engage in assessments and revisions of development plans, one staff member among caregivers should be nominated to analyse the plan regularly with the resident, as part of a meaningful relationship of support and this should constitute the basis of the work of the coordinating staff, in collaboration.

Personal development plans are part of a life project and as such they should include careful assessment of what is needed for the individual to transition to some other form of living arrangement rather than assuming that institutionalisation is the permanent and final living arrangement for the resident (4.7). Currently, the personal development plans used by the visited institutions do not include any deinstitutionalisation dimension, which they should and that should be mandatory. No matter how unrealistic for a specific individual the idea of transitioning from institutional care to community-care may sound, assessing what would be required for that to take place if that is the wish of the person involved would still be very useful. It would be useful to better understand what persons prefer, on the one hand. But it would also be very useful to establish priorities, even in terms of policy decision and implementation, at the local and the national level. Drawing a deinstitutionalisation plan is about knowing what the person needs if he/she was to reach a certain desired outcome. Whenever the desire for living in the community is expressed (as it was by all interviewed residents) it should be at least possible to have a baseline assessment about what would it take for that to be possible.

Finally, personal development is a holistic project by definition and so should be the personal development plans (4.8). They should include all dimensions of life and not be so focused on the strict areas of service provision for which the institutions are directly responsible. The definition of the individual project should articulate areas such as healthcare and healthcare services, education and training, work and occupation, leisure, culture and sports, transportation, assistive devices, and technologies, involving external agents as adequate and celebrating agreements of service provision that include aspects beyond the scope of direct action of the institution. This requires training of teams to work with outside agents, public and private, local, and national, as well as the increase in the number of technical staff involved. It is however a fundamental aspect of a real project of personal development.

Health and healthcare

Living healthy is consensually agreed to be fundamental for the enjoyment of a good quality of life. In terms of service delivery in residential care institutions, this cannot be just a question of providing healthcare, but it must also include supporting residents to take responsibility for their health and be proactive in the pursuit of a good health condition (4.3). To do that, institutions must offer residents the opportunity to have access to information, in and outside the institution, on several aspects such as diet, substance abuse, exercise and physical activity, sexual and reproductive health, among others that may be found relevant for the specific needs of each resident. Residents must also be supported in choosing what is better to stay healthy. This is in fact one fundamental aspect of autonomy and freedom of choice: having alternatives to choose from and being supported in making the best choices. Once more we are here presented with critical areas of life that concern abilities and skills individuals should have the opportunity to develop to secure successful transition to community-based living arrangements.

This would also shift the emphasis from acute healthcare to preventive healthcare. Currently, healthcare for residents is mostly focused on responding to acute episodes that require medical attention or follow-ups of diagnosed conditions. Check-ups are not common in most institutions, and this is particularly evident in dental care. Although the national guidelines issued by the regulator to help service-providers organising for services emphasise the need for regular dental care and routines of dental hygiene, the reality of visited institutions falls far from the desired scenario.

On the one hand, and since this is an area of provision underdeveloped in the national healthcare system, resorting to private, often costly, services are the only way to secure dental treatment. Payment for those services falls on the resident, which introduces some inequity problems, with residents benefiting from stronger family support being in a better position to secure dental care and generally better preventive healthcare services than those with no family support or from poorer backgrounds. The same applies to other specialised areas of care provision such as eye-care. Better articulation with healthcare providers and the inclusion of preventive healthcare in personal plans is fundamental as a first step to secure residents have access to good health. Personal budgets for healthcare may need to be considered to face the costs of healthcare of residents considering their specific needs and to prevent inequity in access (4.9). There are national experiences used with other groups of the population that have proved successful in this area, such as the dentist-cheque programme that awards vouchers to children up to the age of 18 or to older people in situation of poverty that can be used in the private practice of dentists to secure oral health treatments.

Finally, and still on the healthcare front, residents with mental health problems must have access to appropriate services in appropriate settings. In the visited institutions there were too many cases of multiple diagnostics and staff is not trained to deal with psychiatric disorders (4.10). In fact, some practices of restraint are triggered by the low skills of the staff to deal with psychotic outbreaks and other episodes resulting from mental health conditions. The articulation of these residential care institutions with services offering mental healthcare is therefore fundamental and needs to involve routine assessments and consultations with specialised healthcare professionals, according to the needs of each resident.

Education, training, and work

There were 320 individuals registered as residents over the period which visits to the institutions took place. Among those 320 individuals, 219 were attending the CAO daily, 7 were engaged in some training programme to learn a profession or in an education degree and only 3 were in regular or protected employment. This is certainly one of the most important areas of improvement within the broad purpose of promotion of personal development.

In the majority of visited institutions, it was possible to observe that, for most of the staff, personal development involves primarily keeping people occupied during the day. Almost all residents are expected to attend the CAO, and this is the main *locus* of promotion of personal development by utilising the so-called meaningful activities. It falls beyond the scope of this report to write about the CAO, a service the expert considers needed revision as it has operated too close to the schooling model offering almost exclusively activities that involve arts and crafts, like the ones found in childcare services. New legislation has been published and introduce a new framework for this service, rebranded to CACI (Centre for Activities and Capacitation for Inclusion). At the date this report was written, institutions were going through the process of adapting the existing CAO service to the new CACI. It is too early to assess the results of such a change. At the time of the visits by the expert, CAOs did not seem to be working as places where residents have the chance to develop personal skills and competences in preparation for a broader participation in the community and even less in preparation of transition to living in the community. Meaningful activities that can perform as surrogates to engagement in the labour market are found in some CAOS, with some experiences leading to the production of goods that are even sold outside in the market. This can be a relevant path to follow, especially for those for whom integration in the labour market is not a realistic goal. As a broader principle, though, one should be more ambitious in how personal development is tackled and this certainly does not include keeping individuals occupied just for the sake of distracting them.

Irrespective of how CAOs operate, projects concerning the professional development of residents, of their skills and competences to engage in meaningful, and ideally productive activities should rank high in their respective personal development plans. It will be an important facet of any project of deinstitutionalisation. This may involve third parties rather than being confined to the scope of services the institution provides, as it seems to be the case at present. Education, training, and opportunities to integrate the labour market are to be considered as key components of the life project of the resident, according to his/her needs, characteristics and wishes, and need to be tackled in pursuit of the realisation of the full potential of individuals concerned. This is very central for the development of long-term projects that may even include deinstitutionalisation projects (4.4).

At present, being admitted in the residence is seen as an end-of-the-line condition, with no transition to life in the community being seriously considered. This partly accounts for the low importance professional development seems to have in the personal plans of residents. The shift must be such as to include in the diagnostics component the expectations and abilities of each individual, the appropriate plan of education and training and the measures to be put in place to support integration in the labour market or in some equivalent setting. This needs to come with the definition of targets and calendars that set a realistic horizon for the realisation of the individual project of life and that open ways for a real personal development. As much as possible and adjusted to the needs and expectations of each resident, regular employment should be the preferential goal, protected employment would come next and if those are not possible, then the socially useful and meaningful activities. What is not recommended is the continuation of a model of occupation of time with no meaningful purpose. Engaging in work and meaningful activities does not need to be fundamentally at odds with living in an institution and should be addressed as such.

Leisure and culture

The opportunities to enjoy and participate in leisure and cultural activities are constrained by dual barriers: barriers to participation for having a disability and barriers to participation for being in an institution. However, some things can be improved to overcome some of those barriers and create more fulfilling opportunities for the residents of visited institutions.

The location of the residential care units certainly poses some unique barriers, with distance preventing individuals from engaging with the community (4.11). When this is coupled with the absence of transportation opportunities, the exclusion of residents is total. Improving public transportation opportunities in the cases where the facilities are distant from the city or village would be a positive contribution. In fact, one could go even further to suggest that it should be mandatory as part of the public service nature of urban transportation systems to secure that social care facilities of all types, including residential units for persons with disabilities, should be included in the network of public transportation routes. This is an aspect that could also be supported with European funds.

Physical barriers are still a relevant aspect to highlight, despite the developments in national legislation concerning inclusive accessibilities. Local municipalities have a key role on this issue as they are the ones in a better position to trigger the necessary adaptations of public and private providers of services.

Attitudinal barriers are also a relevant obstacle to the participation in cultural, sports and general leisure activities outside the institution. These involve the staff of the institutions, who emphasise the risks involved in outside activities, and the demanding nature of the logistics required to avoid those risks. Attitudinal barriers also involve the community in general, that continues to see the residence as the place where people with disabilities should stay, separated from the rest of the population, mostly for their own good. Campaigns and initiatives to work around these broad attitudes towards disability are still very much needed and should be supported, namely in terms of funding (4.5).

Financial barriers are also an important aspect that needs to be mentioned (4.12). Most residents lack the income to shoulder the costs of participation in activities outside the residence. If a resident, for example, wants to take the bus to go to a football stadium to watch a football game, the costs involved in such an activity would be too high and service providers do not have room to accommodate this type of extra costs. Again, inequity issues come to surface, especially if one keeps in mind that most residents accumulate problems of social exclusion and poverty. Personal budgets to participate in leisure activities, sports, and cultural events, according to individual needs, capabilities, and expectations, could be an important tool to overcome financial barriers to participation of residents in institutions in some activities that require entrance fees.

Overall, service providers may need to revise some aspects of how they tackle leisure and culture. On the one hand, and thinking about the activities organised inside the institution, these should be planned with the residents rather than imposed as part of a menu of pre-defined activities. Residents should not feel obliged to participate in all activities and the possibility for individual or smaller groups activities should also be considered. On the other hand, thinking about the activities taking place outside the institution, these should not be organised as "visits to the community". Participation in activities outside the institutions should be regarded as part of what is a normal life, according to individual needs and preferences. For this to happen, several aspects must be improved: residents must have access to information on cultural and sports events taking place in the community and supported in organising for their participation in those, if that is their wish; residents must be offered support with transportation and personal assistance, if needed, to participate in whatever activity they wish and within reasonable arrangements.

Municipalities have a critical role in this topic as they are the ones that control the licensing of events. They can be stricter about events being inclusive and accessible. They can make the beach accessible to all (e.g. to people in wheelchairs) to allow persons with reduced mobility to participate in one of the most common leisure activities of any regular Portuguese citizen: going to the beach in summer. In fact, having holidays and spending time outside the usual place of residence is one of the indicators included in the social indicators of the EU, as it is considered part of what characterises a normal lifestyle in Europe. There is no reason for that to exclude those living in residential care facilities. Financial and logistic conditions should be secured to offer this opportunity to those residents who wish to do so (4.6 and 4.13).

Dimension 5. **Mainstream citizenship rights in service delivery**

Despite the proliferation of guidelines, recommendations, and political statements about the social inclusion of persons with disabilities, living in an institution still means being primarily treated as a disabled person rather than as a full-fledged citizen. Breaking up with this is probably one of the biggest challenges, one that does not concern only institutions providing residential care services but rather the entire society and how society sees persons with disabilities. In this report, the expert zooms in and looks at some specific areas that present themselves as more urgent in residential care settings and that can benefit from improvement in view of securing the rights of citizenship of residents.

Recommendations for securing the rights of citizenship of residents	
Service providers should	
5.1	secure all residents have access to information in formats accessible to all.
5.2	secure all residents have access to information proceeding from outside the institution.
5.3	work with all relevant agents to support residents in establishing communication with public agencies and services and with organisations representing the rights of persons with disabilities.
5.4	guarantee residents are always informed about daily routine operations and in accessible formats.
5.5	be proactive in promoting civil and political rights and include those as an element of personal development in individual plans of residents.
5.6	train their staff to recognise signs of discontent, concern, or complaint among residents, especially those that may not be able to communicate by other means.
National authorities should	
5.7	promote the widest dissemination of information about inspections and audits, including access to audit reports and contacts of auditors. Information on these should be written in a way that is accessible to all, targeting the residents, relatives of residents and staff working at the institutions.

National authorities should (cont.)	
5.8	**join sectoral bodies and service providers** and work together to promote the attitudinal change among all agents involved, including residents, towards looking at all persons with disabilities as able to make informed decisions, even if support is needed, instead of assuming they are not.
5.9	find ways to introduce some independent assessment in the decision-making support system of residents in institutions.
5.10	work with organisations representing persons with disabilities to find effective methods to encourage and support residents in institutions to access any forum where their civil rights are being discussed.
5.11	work, in collaboration with service providers and sectoral bodies, to improve the referral and admission system in institutions considering rights and impartiality in assessment of needs.
5.12	consider the inclusion of a plan of deinstitutionalisation as mandatory in service agreements signed between resident and service provider.
5.13	work with service providers and sectoral bodies in the revision of protocols to deal with complaints to ensure transparency, accountability, and confidentiality.
5.14	work with the Ombudsperson services to adapt the existing mechanisms of access of citizens to the ombudsperson to the specific characteristics of the settings where residents in institutions live.

Explanatory Notes for the Specific Recommendations

Information

Being informed is a condition to be aware and acknowledge one's rights and to be able to exercise them. This is a critical area that showed some worrying gaps in visited institutions and that can be tackled in several manners.

First, it is fundamental that all residents have access to information in formats that are accessible to all, including the use of language adapted to their needs (5.1). For example, fundamental documents related to the operations of the institution, and that are even considered of mandatory exposure by the regulator, are available on display, at the entrance of the residence, locked inside glassed windows. Most residents were completely ignorant about the contents of such important documents and were unaware of the dispositions concerning their rights as residents.

Second, it is important to secure open channels of communication so that the resident can have access to relevant information proceeding from outside the institution and be able to communicate with whoever he/she wishes to do so (5.2). Under this area the expert includes securing access to the Internet, facilitating access to magazines and newspapers, securing access to a phone line, including support to use one if needed and/or requested by the resident.

Third, and once communication channels are secured, residents should be supported in the creation of opportunities to communicate with other services, including advocacy and emergency services (5.3).

Service providers should create and distribute a brochure, in formats accessible and adapted to different individuals, with information on the service provider itself and on the services it supplies. This brochure could also include a statement about the purpose of the institution. In this brochure it should be clearly outlined the rights of residents and information on how to access an advocate or an advocacy service.

It would also be important to grant access, to residents, relatives, and staff, to information about when and how residential services are inspected, as well as to inspection reports (5.7). In fact, the Social Security services in charge of these routine inspections should be available for contacts from the residents, staff, and the relatives of residents, with contacts of inspectorate services being widely disseminated in advance of visits by inspectors.

Information is also an important part of daily routine operations, and residents should be regularly informed about the day-to-day arrangements of the service and consulted about developments and changes, including on issues such as the staff on duty, changes to services and activities, schedules, meals, etc. (5.4).

Informed decision-making and consent

This is a very important domain of rights for individuals living in residential care institutions. In the 11 visited institutions, among the total 320 residents present at the time of the visits, 232 were included in the support to decision-making scheme. The change in the legislation that took place in 2018, as already discussed, was an important step in the direction of the safeguard of the right to participate in decisions that concern one's life, moving from a legal framework based on interdiction and guardianship of persons with disabilities to one of support in the process of decision making. The Scheme of the Adult Supported is very recent and when they had the visit of the expert, institutions were still in the process of formalising what were previously situations of guardianship of residents, substituted in decision-making by their guardians, often the director of the residential care institution. It is still early days to make a solid judgement on the implementation of the new scheme, but it is reasonable to assume changes in daily practices will not be easy to implement just by decree. There are aspects that will be critical for a successful move from a paradigm of guardianship to one of supported decision-making in institutions and that should be considered as the new legislation is being implemented. The expert's recommendations address those complementary actions.

Firstly, there is the need to trigger an attitudinal change among the staff working in the institutions, at all levels, and among relatives of residents and residents themselves (5.8). For the new scheme to have real impacts in people's lives, residents must be assumed by default as able of making informed decisions and not the opposite. Also, it is necessary that all stakeholders understand that when support to make informed decisions is needed, support must be secured – and that support is not substitution. Institutions have been operating in a completely different mindset for decades and it is not reasonable to assume individuals will suddenly change their practices, and even less their attitudes. On the contrary, if there is no serious and continuous investment in training of staff in institutions, in dissemination of information and campaigning next to families of persons with disabilities (and the entire community as a matter of fact), it is likely that the change in the legal status imposed by the new legislation will not represent, in practice, any significant change for the lives of residents and for their control over the decisions taken, on a daily basis, on issues concerning their lives, so that their wishes and choices are respected and implemented. This will be a critical dimension to sustain a project of deinstitutionalisation as well.

Secondly, there is the need to introduce some element of checks and balances in the system, something that is not included in the legislation (5.9). At present, for residents who are under the support to decision scheme, the person nominated to provide that support is either a close relative, typically parents and/or siblings, or the director of the residential care facility. In both situations, the expert considers there are enough potential conflicts of interests to justify the introduction of some outside impartial cross-checking. The main goal of such an impartial cross-checking would be guaranteeing that the wishes and choices of residents are in fact being respected and that the interests of the residents are the ones that are being safeguarded and not those of the relatives and/or of the service-provider. As it stands now, residents in the visited institutions have no access to an advocate or an advocacy service of their choice when making decisions. If they want to appeal against a decision implemented against their wishes, they have no opportunities to pursue any legal action. It would be therefore of critical importance that the regulator calls upon itself the task of introducing a verification system or an independent support system to assist residents in residential care facilities in making decisions, at least in what concerns decisions about fundamental aspects of their lives and their stay at the residence.

On this, there is something to learn from the Swedish experience of the "personal ombudsman" (PO), originally created for psychiatric patients after the 1995 reform of the psychiatric system, and later expanded to people with complex disabilities for whom guardianship is often presented as the last resort[11]. In summary, it would be interesting to test-pilot the creation of brigades of POs, working independently from the social care services and from relatives of residents, to work directly with the residents in the residential care facilities and support them in decision-making processes, simultaneously acting as the defenders of their rights and interests. The model could be run by NGO's if they have no interests in the social care services sector or directly by public authorities, possibly with the collaboration of local authorities to allow for a decentralised system. It is not possible within the scope of this report to outline a detailed plan for such a system. The main goal is to highlight the importance, as already mentioned before on other topics, of introducing some independent assessment element in the system of service delivery putting the interests of the residents, in an impartial manner, at the centre. If ever confronted with the possibility to transition to community-based living arrangements, it will be critical for individuals to be able to count on that support. As such, it is a measure that has a potential impact that largely exceeds the space of institutional care dynamics.

Civil and political rights

What was observed in many of the visited institutions concerning civil and political rights is part of a wider alienation of persons with disabilities living in institutions, an aspect of their segregation from community life. The specific aspects falling under this have been already touched upon in previous sections as all things are interrelated.

Some aspects that could be improved and that would concur to the safeguard of fundamental civil rights of residents, concern firstly supporting and facilitating, when the resident so wishes, the expression of views and opinions (5.5). During the visits, and as residents would engage with the expert, it became apparent how important for many that encounter was, as it was described by interviewed residents as very rare the opportunity to be heard on any topic. Secondly, it is important to be proactive in securing the right to participate in the political process, namely by voting. Although all interviewed directors of visited institutions would state that if any resident would want to vote he/she would be assisted in doing so, the reality is that hardly anyone does it and the level of political alienation found was very high. If people are not aware of their political rights, if civil and political rights are not part of the personal development work carried out at the institution, then it is unlikely individuals will show any interest in the topic and therefore will be objectively deprived of exercising an important citizenship right. Being part of a community is not just about the location of one's residence. Deinstitutionalisation, in fact, is not just about changing one's postal address. It is about being a full-fledged citizen that actively engages in all areas of citizenship. And therefore, the importance of addressing these aspects, even if the individual is in an institution, in preparation for transition to community-based living arrangements.

For all this to happen, it is fundamental to guarantee residents have full access to information as any other citizen (5.10). This should include supporting and encouraging residents (but staff and relatives as well) to access any forum where their civil rights are being discussed and where policy programmes and decisions are being considered. The recent example of the public consultation process of the national strategy for persons with disabilities offers a good example of what should have been, and was not, a moment of intense dissemination of information in the social care sector to reach residents in institutional care and guarantee their inclusion and participation in the public consultation of such a relevant policy programme that directly impacts their lives. With very few exceptions, most directors of visited institutions were oblivious of the national strategy and had

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[11] See more on the Swedish PO at https://europe.ohchr.org/EN/Stories/Documents/MathsJesperson.pdf

not participated in the consultation phase of its elaboration. Among the interviewed residents that was also the common trend.

Admission processes and individual service agreements

All procedures concerning admission and service delivery agreements are very clearly outlined in the documents each service provider elaborates for that purpose, namely in what concerns rules of eligibility and criteria of assessment for admission. All is defined in the light of current legislation in place and audits from the Social Security Services tend to focus a lot on these aspects.

Despite the clarity of the documents that frame admissions and service contracts, in practice the Portuguese model involves a system where service providers are private institutions that sign cooperation agreements with the State, and under those agreements the State pays for the service that is being delivered by the private service-provider, but with institutions being almost completely autonomous in the definition of admission criteria and in the management of admissions. It is a system that creates, in its architecture, room for arbitrary decisions. Admission criteria are set by the institutions, and it is the institution that analyses the applications and makes the final decision about admitting or not an applicant. How to articulate this with a framework of rights of citizenship is the question that remains unanswered in a system offering a public service by means of a private provision. Who is in and who stays out is a decision that is ultimately under the exclusive control of the service provider (5.11). And although this raises an issue that involves a systemic change, there could be some benefits in evolving to alternative models of management of places available and of assessment of applications, maybe learning from the positive aspects of the Integrated Long-Term Care Network (*RNCCI – Rede Nacional de Cuidados Continuados Integrados*)[12] created in 2006 to manage, at the national level but based on regional coordination teams, the placement of individuals in need of long-term care after being signalled at hospitals or health centres. Although addressing a different area, the experience of the RNCCI is worth assessing from the perspective of equity and fairness in terms of access, since the placement is not fully controlled by the final service provider but rather managed by teams of professionals that respond to public authorities and that are, in principle, in a better position to guarantee that selection is based on rights and impartial assessment of needs.

What the expert could learn from the visits to the 11 selected institutions is that they had, at the time of the visit, a total of 320 residents and a total of 361 individuals enrolled in a waiting list for admission. To what extent individuals are in more than one waiting list, it is not possible to know at present. A more centralised, integrated model of management of places available and selection of applicants could also represent some gains of efficiency in terms of waiting lists.

Once admission is decided, the processes leading to the signing of the service agreement are also clearly regulated and all institutions tend to follow the same model. In this domain, the most pressing aspects that should be improved concern the actual involvement of residents in the process and the need to include in the service agreement the plan of action that would be required for the resident to leave the institution if possible (5.12).

Looking at the involvement of prospective residents in the process leading to the signature of the service agreement and the actual admission, although the participation of the client is defined as the rule in the regulations for the sector, in practice this participation is very residual, if any. It is the relatives, or the social

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[12] See http://www.acss.min-saude.pt/category/healthcare/long-term-care/ for details about the RNCCI.

services representatives by order of the court, that take care of the admission and of the details of service agreements. More effective involvement of prospective residents would be welcomed.

Looking at the contents of service agreements, what is stipulated in the individual plan of development concerning the creation of conditions for the prospective resident to be able to return to life in the community should be included as part of the service agreement. This would be expected in a model of service delivery that actively pursues deinstitutionalisation and should be made mandatory. Deinstitutionalisation may mean different things for different individuals, also considering their preferences and expectations. It could be transitioning to an autonomous house or fully transitioning to his/her own place of residence. It could involve integration in the system of support to independent living, with the allocation of a personal assistant. There is not a one-size-fits-all response. The importance of including it in the service agreement, at least for those individuals where that is a feasible approach, is that it makes it a binding obligation to the service provider. In doing so, the service provider would be mandated to work with third parties, other service providers, for example independent living services. By doing so, the service provider would be contractually obliged to provide support to transition, something that is totally absent from any document, template, or minute of contract analysed by the expert.

Complaints

The main challenge in what involves complaints, and the related procedures is, once again, the challenge of changing attitudes. The way complaints are dealt with is primarily influenced by the organisational culture and by the extent to which the organisational culture welcomes feedback and openness. Training of staff, namely that with coordination responsibilities, remains an unfinished story in these aspects of organisational culture.

The principal recommendation the expert would highlight is that the processes around complaints filling and analysis are too bureaucratic, leading to a focus on rules and processes rather than on the contents of the claim (5.13). In fact, not all issues need to be formalised, as some complaints could be solved in loco immediately, typically those concerning routine aspects of the daily life of the individual. In a setting that promotes a culture of respect of autonomy, freedom of choice, and self-determination, this would probably be the natural path to follow. Formalisation in turn should be primarily prepared to deal with more fundamental issues, concerning basic rights and freedoms, aspects of functioning of the institution and others that are not easily solved within the relationship of support between resident and caregiver.

Currently, there is no real protocol for dealing with complaints. The reports of occurrences deal with out-of-the-ordinary episodes, which could very well lead to complaints, but as the system is assembled the resident has no control over the registration of an occurrence so it can hardly use it as an instrument to formalise complaints. This is one dimension that urgently needs the introduction of some mechanisms of transparency. Residents must be informed about how and where to file a complaint. This cannot be overly centralised in the director of the residence, which tends to foster a paternalistic approach rather than a client-service provider relationship. On the other hand, protocols in place must ensure confidentiality and safeguard the resident against adverse consequences – suggestion boxes do not play that role as they are placed in plain sight. Additionally, suggestion boxes are not accessible to those not able to write and handwriting of those who can write would be easily identified by the staff. Residents must also have access to varied modes of complaint, including access to the National Ombudsperson. The Ombudsperson services in Portugal include a dedicated service that receives complaints about issues affecting persons with disabilities – it is the Hotline for Persons with Disabilities[13].

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[13] See more at http://www.provedor-jus.pt/?idc=56

Knowing about this service, having access to a phone line, getting the support needed to use the phone line and communicate, would all be pre-requisites for residents of visited institutions to be able to access their representative as citizens. This is what institutions should focus on doing if interested in promoting an open culture of feedback and respect for rights (5.14).

Transparency is also important in how complaints are dealt with. When a complaint is filled, residents must have access to the complaint log and be offered a response as soon as the investigation is terminated. Institutions in turn, should use complaints to monitor and improve their operations (5.13).

Finally, another area of training of staff that would be important to promote concerns helping staff to recognise the signs in behaviour that may indicate an issue of concern or a complaint that the resident may not be able to communicate by other means (5.6).

Dimension 6. Improve physical environments

Space has a big importance in how people live. Addressing it towards the end of the list of recommendations should by no means be taken as a sign that the expert feels it is less relevant than other aspects already discussed. It is actually the opposite. Life unfolds in physical environments, and these can work either as facilitators or as obstacles to achieving good quality of life.

The starting point is slightly different and reflects a conscious decision that results from what was observed in visited institutions. Visits have shown how important space is and how strong are its impacts on the lives of residents in institutional care. But space cannot be addressed as the sole or even the most important determinant for the quality of life in institutions. This is the approach that the expert has found in many of the visited institutions and that leads them to believe that once they solve all their problems concerning space and living environments, the path to safeguarding fundamental rights and freedoms will be secured. Space can certainly create obstacles or be a facilitator in that path, as stated above. But the path will only be secured if aspects of organisational culture and human behaviour are aligned. That is why the expert has chosen to approach first the immaterial elements of how services are organised and delivered, leaving space for last.

The recommendations put forward under this dimension, in a total of 6, are not targeted at institutions that fail to fulfil the very basic requirements that need to be met for licenses to be issued. For those, the only recommendation would be immediate closure so that renovations or new constructions can take place. This is something that falls under the exclusive responsibility of the regulator and failure to act upon situations that violate the fundamental right to live in a safe and healthy environment is unacceptable and requires no additional consideration. Among the visited institutions, the expert could locate 2 that would fall under this. One is already in the process of moving to a new facility. The other is not, and urgent action is required to move residents to a safer location while sorting out how and when a new residential care unit can be built.

The expert has decided to focus her recommendations on aspects that must be improved and tackled in a second order once the basic conditions are secured. Those aspects include how space is designed, where residences are located, and how health and safety issues are addressed.

Service providers in the residential care market must meet some technical requirements, defined by law, that set minimum standards required for a service provider to be licensed to operate[14]. Those standards relate exclusively to listing the spaces that must exist in the residence, according to their function, and the size each

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[14] See the legal diploma at https://dre.pt/web/guest/pesquisa/-/search/66639520/details/normal?_search_WAR_drefrontofficeportlet_dreId=66639515

space must have considering the number of expected residents. Standards concerning the layout, decoration, and other aspects of what constitutes the appropriation of the space by those living in it are absent from any mandatory standards. There are some manuals published with the sponsorship of the Social Security services that offer recommendations about how to organise the space of an institutional care facility. In those manuals one can find very relevant recommendations, many of which aligned with some of the topics that have been raised in this report. These documents, however, do not seem to have a significant impact in how service providers organise their services and the spaces where those services are offered, as the visits to institutions by the expert of the report have shown. One needs to ask why that is and try to change it. One strong hypothesis is that the guidelines are just recommendations and not requirements.

In this section the expert will address three aspects of the physical environment of visited institutions that can benefit from improvements in the light of a rights-based approach: the living environment where residents live their lives daily; location and accessibility; health and safety.

Recommendations for the improvement of the physical environment of institutions

Service providers should

6.1 consider projects of adaptation of their existing facilities to bring the layout and functionality of spaces closer to an environment where residents can be fully engaged in the several dimensions of what constitutes a normal life, consulting with them to inform these adaptations.

National authorities should

6.2 trigger change in the living environment offered by institutions by means of revision of existing rules concerning size (promote downsizing), type of services (avoiding as much as possible multiservice), layout of spaces (strengthening individual uses of space) and equipment (securing accessibility to physical and digital environments).

6.3 work with municipalities to secure appropriate locations within the community for residential care facilities in view of avoiding spatial segregation of persons living in institutions. For those located in the outskirts of villages and cities, public transportation should be made available to include the location of the institution in the respective public transport network.

6.4 work with sectoral bodies, organisations representing persons with disabilities and experts from the academia in the elaboration of educational materials, campaigns and training programs that promote the mainstreaming of accessibility as social inclusion.

6.5 work to revise urgently the system in place to manage access to assistive devices, improving waiting times for access to equipment and rules and procedures concerning financial aspects of acquisition.

The European Commission should

6.6 continue to use structural funds to support projects involving the adaptation of existing residential care facilities that want to downsize and transition to a person-centred and rights-based approach to service-delivery aligned with the UNCRPD, namely transitioning to autonomous houses or shared self-served residential units in the community. One specific area of investment to highlight concerns access to digital environments.

Explanatory Notes for the Specific Recommendations

The living environment

There is wide consensus about how residential care facilities should feel homely and be accessible, promoting privacy, dignity, and autonomy of their residents. Most of the places visited by the expert still feel very institutional, almost like a healthcare facility.

For the existing institutions, the challenge will be finding the best adaptations to turn the existing facilities into something that feels more like a home. For the ones that may be built new, and considering that there are new funding programmes being launched to build new institutional care facilities for persons with disabilities, namely under PARES, the philosophy of designing new facilities must be completely changed: new projects must be thought as designing a normal home with some adaptations, rather than designing an institutional care facility with some improvements (6.2). The model the expert has visited in one of the institutions offers a good example, replacing the architectural model of a building with bedrooms and complementary spaces for communal use by self-served residential units, small flats, similar to what one can find in serviced housing in the sector of services for older people.

Currently, the funding programs in place may not be comprehensive enough to support this vision (6.6). The programme of funding PARES 3.0, the last issued for the sector with national funds, defined rules for the funding of new facilities and for the adaptation of existing ones. What the expert found in the rules for funding under PARES 3.0 is a continued focus on size, function, and safety of spaces to be built. Despite the proliferation of guidelines about aspects of residential spaces associated to rights of residents, sponsored by the regulator, the persistent absence of any mandatory dispositions, at least in the form of eligibility criteria, in the funding rules probably explains the very modest impact of the guidelines themselves.

Firstly, size of residential care facilities remains an unsolved issue. The funding program PARES 3.0 points, again, to facilities offering 30 places. The fact that the evaluation criteria for the decision on applications considers capacity as a factor to weight, establishing the principle of maximum capacity being prioritised in terms of investment is likely to motivate service providers to continue building sizable units, rather than smaller group homes.

Secondly, multiservice is still the option signalled as the preferred for service providers that apply for funding for the construction of new residences. This is something the expert sees as negative. The expert argues that residences should be precisely that and just that – the home where residents live. If residential care facilities remain integrated with other services, namely CAOs or CACIs, it will be even more difficult to create the home feel these places should have. The bigger the units and the more services they include, the more likely it is to have economies of scale. Even if that may be very cost-effective looking purely at the financial return of investments, looking at it from the perspective of quality of life and social returns may offer a different result.

Thirdly, although funding can be requested for the elaboration of the architectural project and the supervision of the construction, nothing is said about what the expert sees as best practices in this domain: participation of prospective residents, staff, and the community at large in the analysis of the architectural projects; evaluation of proposed projects in light of guidelines stemming from rights and not exclusively from technical requirements related to size per user, mobility, and safety.

Some of the most pressing aspects of the living environment that need to be considered, and ideally integrated in the regulatory framework, and that are applicable to both new builds and to the adaptation of existing residences are:

- Facilities must be equipped to the best of their capacity with assistive technology, aids, and appliances, including accessible information and communication technology. This is fundamental to promote full capabilities of residents but also to help staff in their work (e.g. hoists to move residents with little mobility; sensors to open and close doors).
- There must be private spaces for the solitary pursuit of entertainment and/or for the entertainment of visitors according to the resident's wishes.
- Bedrooms, as much as possible, should be for single use and facilitate private access to bathrooms.

- Bedrooms should be decorated according to the resident's wishes and preferences and opportunities for the personalisation of the space should include the possibility of the resident choosing his/her own fittings and fixtures and bring his/her own furniture if he/she so wishes.
- All residents should have secure personal storage available for personal belongings, in a size that is sufficient for the storage needs of everyone, with access controlled by the residents and ideally inside his/her bedroom.
- Furniture and layout of shared spaces must be sufficient considering the number of users and must offer alternatives for the use of time avoiding block-treatment approaches. As an example, having 1 TV room, with 1 TV set for 30 residents is not acceptable. The same way it is not acceptable to have the area for TV watching and the area for other activities in the same space. Surely, this has implications in terms of staff, as the more divided the space is the more staff may be required to secure the necessary support to residents. However, the expert argues the issue needs to be approached from the opposite angle. If the layout of the space facilitates block-treatment, it is more likely that block-treatment becomes the norm. This, in turn, will facilitate running the service with a smaller number of staff. What the expert suggests is looking at space and layout as allies in the promotion of a new vision of service provision rather than as facilitators of the traditional disempowering one in place for decades.
- Residential care facilities should offer easy and safe individual access to indoor and outdoor recreational spaces and activities to allow for higher levels of control on the resident's side, on how he/she decides to structure his/her day. As a principle, individuals should be able to circulate freely within all areas of the residence, including outdoor areas, and all adaptations needed for that to happen should be put in place.
- As a rule, the layout must facilitate autonomy and privacy. This must be considered in all aspects of layout, and it must be evaluated on a regular basis to identify needs for changes and to implement the necessary adaptations to lifestyles that are, by nature, dynamic.

In the realisation of all these aspects, it is very important that residents, their relatives, staff, and all relevant stakeholders are involved and offered the chance to participate and be consulted in decisions concerning the use, the layout, the furnishing and equipping of spaces.

Location and accessibility

Location of residential care units is an essential condition for the realisation of the right of persons with disabilities living in institutional care settings to participate in the community. Spatial segregation is just the first step towards the full segregation of residents in institutions. At present, there are recommendations, from the regulator, about the location of residences but no mandatory rules, which ultimately allows for spatial segregation to continue as a common trait of residences for persons with disabilities.

For the situation to change, the involvement of local municipalities is critical, as they are the ones in a better position to secure appropriate locations and safeguard institutions against the speculative pressures setting prices of land in the centre of villages and cities at prohibitive values for service providers with limited funds available. On the other hand, it is important to move away from a big-size type of institutions, that require big plots, to a model based on smaller units, that will require smaller plots of land. This will not only facilitate access to land, but it can also allow to pursue the rehabilitation of buildings that may be vacant and that are more centrally located (6.3), not to mention all the advantages small size also offers in terms of quality of life of residents.

Thinking about the institutions already operating and located in the outskirts of the villages, local municipalities must work towards the expansion of the network of public transportation to secure the facilities are included and take the necessary action to guarantee the surrounding areas are safe and inclusive to facilitate the pedestrian circulation of residents, allowing them to participate to the best of their abilities in the surrounding community.

As for accessibility, an attitudinal change is required, including among policy makers, to understand that accessibility is not just about compliance with a set of minimum standards focused almost exclusively on mobility issues and safety. Accessibility is about inclusion and needs to be assessed considering the individual and re-evaluated regularly to accommodate changing needs and the dynamic nature of life (6.4). Alongside the general rules, there must be room to introduce the necessary changes according to the uniqueness of the residents in each setting, like what one would find in a normal home considering whoever lives there. As an example, if some residents in an institution are on wheelchairs, the height of displays must be adjusted so that individuals can have materials on display within their angle of sight. But if there is no resident on wheelchairs, that adaptation may not be necessary. And others may. In a nutshell, it is fundamental to rethink standards for good practices in what defines inclusive design and accessibility in residential care facilities, promoting a model primarily focused on the specific needs of each resident considering the characteristics of the facilities, rather than on using checklists of standardised items that tend to set minimums. The elaboration of guidelines for the adaptation of spaces, with the ample participation of all relevant stakeholders, and considering the best practices documented internationally, would be welcomed, and could assist service providers introducing the necessary changes.

Health and safety

This topic takes us back to the discussion about managing risks and about how to conciliate safeguarding the health and safety of residents with the promotion of autonomy and good quality of life.

While complying with the legislation in place, service providers must find ways to support residents to understand and manage situations and places that involve an element of personal risk as part of their individual development plan (6.1). There are some spaces in institutions that concern quite relevant aspects of daily life and that are planned and operating almost as an industrial site. Consequently, and because of the way they were conceived, they tend to be off-limits to residents, under the argument it would be unsafe for individuals to access those premises. The argument is in fact correct, as it would be very unsafe for any resident, or for any ordinary citizen, to access an industrial laundry room, not due to the disability, but primarily due to the absence of skills to operate the machinery involved in those units. However, being involved in taking care of one’s laundry is arguably an aspect of what can be considered a normal life, and one to which the resident should have access, considering any needs for support.

This is, of course, a quite intricate analysis, as all things end up being related to each other. Again, if one thinks about the size of the residential units, and if the regulator continues to promote big units to house many residents, plus serving the users of other services (the CAO/the CACI), then the supporting services will also tend to be big. As they become bigger, they become more distant from the residents and eventually off-limits. Smaller size units would certainly allow to plan things differently and offer more opportunities for residents to be fully engaged in all dimensions of what constitutes a normal daily life.

Another aspect of how spaces are organised, physically, that impacts health and safety concerns the availability of assistive devices, that display appropriate and accessible standards (6.5). This is an issue that needs to be improved, namely in what concerns the time it takes to make devices available after request and the funding rules based on reimbursements. Some institutions do not have the financial capacity to purchase devices and then wait to be reimbursed by the State.

Dimension 7. Mainstream a rights-based approach in governance and management

This last dimension is probably the one where the roots of many of the others can be found but simultaneously the one where it may be more difficult to trigger changes, at least in the short term. Most of the recommendations offered in this report will only be successfully implemented if the overall organisational culture of institutional care facilities changes significantly to align with a rights-based approach, which ultimately challenges institutions to improve governance and management models. At the end of the day, this is a challenge to the entire system, one where all stakeholders must be involved.

Although aware that systemic changes are hard to achieve, the expert would like to raise some specific issues that can be addressed within the existing social care system and that could represent a step forward in the direction of an agenda of rights. The expert's intention on this is to offer some lines of thought that may be used to trigger a wider discussion, at the national level, and with the participation of all relevant stakeholders. That discussion should concern the future of institutional care for persons with disabilities in Portugal, and the path of change required towards a horizon of rights, illuminated by the principles contained in the UNCRPD and in other relevant charters of rights, paving the way for a successful policy programme of deinstitutionalisation.

Recommendations for mainstreaming a rights-based approach to governance and management	
Service providers should	
7.1	operate a paradigm shift from delivery of care services to delivery of support services.
Sectoral bodies should	
7.2	**together with service providers** approach the academia and engage in partnerships that sustain training and consultancy programs in view of changing models of governance.
National authorities should	
7.3	make it mandatory that residential care services operate only in dedicated spaces with no other use besides residential support. There should not be any room for economy of scale approaches that pool some aspects of functioning of the residential service to other services (e.g., preparation of meals, laundry service).
7.4	work with sectoral bodies to develop a long-term plan of training of all relevant stakeholders to launch the basis of a truly new paradigm of governance in the social care services sector for persons with disabilities.
7.5	create dedicated lines of funding or technical support teams to assist IPSS' boards in restructuring organisational practices in the light of a rights-based approach.
7.6	work with sectoral bodies and service providers to revise models of assessment of results of service provision shifting from a focus on procedures to a focus on outcomes-reach and impact assessment.
7.7	work with sectoral bodies and service providers to resume the project of implementing a formal system of quality assessment, one that not only sets required standards but also introduces a mechanism of differentiation of service providers.
7.8	not allow service providers operating in the residential care services market to also run independent living centres. The purpose of such measure would be avoiding quasi-monopoly approaches that are quite dominant in the sector of disability services.

The European Commission	
7.9	should consider putting together a European system of verification of compliance with the European Quality Framework for Social Services that awards European quality certificates and use it as a condition for access to European funds.

Explanatory Notes for the Specific Recommendations

Management models

The goal of a residential care institution for persons with disabilities is to offer residential care services that resemble as much as possible a home and not an institution. The name of these places in the Portuguese language is very interesting as it includes the word "home". The official name of these facilities is "residential home" – *Lar Residencial* – which somehow translates what one expects to be the nature of these social care services: a home. And a home is a place where each person lives as he/she wants, a place set out according to his/her needs and likings, and a place where each person can live privately or with his/her loved ones.

Coupled with this comes the principle of service delivery being primarily oriented to the provision of support rather than to the provision of care (7.1). In what is supposed to be their home, residents need support tailored to their specific needs and considering their capabilities to live their lives according to their wishes, deciding to the best of their ability all aspects pertaining their daily activities and retaining as much autonomy as possible, always in respect of dignity and privacy. Residential units should not be managed as places where residents are left to be looked after, as places where residents must be supervised to secure compliance with rules and routines that are defined by others. Residential units are also not to be considered as healthcare facilities, a reminiscence of the biomedical understanding of disability that tends to emphasise therapeutic interventions and treatment like approaches to service delivery. Residents may need therapeutic intervention, but that is something that must be conceptualised as fundamentally distinct from the residential care service, even if it takes place inside, similarly to what happens with someone that remains in his/her private home and benefits from visits from a therapist. Overlapping the two functions will ultimately create room for a medicalised approach to service delivery in the residential setting (7.3).

The path towards a rights-based approach takes time but some specific actions can be implemented to initiate the process, that will probably be incremental rather than based on some sort of disruptive change. In the next paragraphs the expert discusses some of the specific actions she selects as the most important at present and considering the national reality. These are specific domains towards which political will and resources must be pooled as a matter of setting priorities.

Training of staff is a critical aspect of change, already addressed several times along this report. Moving towards a right-based framework involves developing attitudes and competences that most staff do not have yet (7.4). And this concerns all levels of staff and not exclusively, not even primarily, caregivers. In fact, one could make a case to start with the top management, as it is at the top that the management and governance model starts being defined. One could even make a case to start at the national authorities' level, namely focusing on the departments of the regulatory body that license and audit institutions.

Management of service providers such as the ones one finds in Portugal though is a complex issue. Typically, each residential care service will have a technical director, the person in charge of daily operations in the residential care facility. He/she, however, responds to the board of the non-profit institution (IPSS). The board is an elected group of individuals, elected by the associates of the IPSS, and that serve as volunteers. The typical format in these institutions is therefore one where the top management is not secured as a full-time job but rather a voluntary work, usually available after office hours and typically with some difficulties in juggling calendars and deadlines due to limited availability of time. More recently, many organisations have evolved to a more professionalised approach to the management of the institution as a whole and have created the position of general director. This is someone that has a paid job as general director and will oversee all aspects of management of the organisation. He/she however will still answer to the board of the institution.

Although one can find a lot of merit in the model in place, especially if the organisations were to operate primarily as representatives of the interests of their associates, the truth is that what is expected from the IPSS is that they operate almost as a non-state equivalent to the state bureaucracy, delivering services of public interest funded by taxpayers. The model of governance of the IPSS sector in that respect does raise some concerns, especially considering what the expert could observe in some of the visited institutions. It will be of limited impact working at the level of the residential service if the IPSS promoting the service as a whole and its board are not included in the equation. In many cases, if not the majority, the fundamental attitudinal changes towards embracing a right-based approach to disability would be required among the board members, and targeted measures would need to be considered (7.2 and 7.5). To what extent is it possible to think about such measures within the existing regulatory framework of the non-profit sector delivering social care services is a question that remains unanswered, but one about which the expert is very sceptical. Ireland offers an interesting example, especially considering the similarities in the design of the social care sector. In that country it was created an independent agency, the Health Information and Quality Authority that has a mandate to develop standards, inspect and review health and social care services, while supporting decisions on how services are delivered. It is an example worth investigating as the expert sees a lot of potential for replication in Portugal, namely separating the roles of funding and inspecting.

Quality assessment models

On a more practical or technical note, the management of residential care services would also benefit from focusing more on performance and outcomes-reach rather than, as it happens currently, on protocols and procedural assessments (7.6). For this to take place it is necessary to act in different fronts. On the one hand, the management of the services would require training. On the other hand, the regulator would also need to revise some of its own protocols, namely guaranteeing that regular audits and inspections do not involve solely a checklist of procedures to count how many boxes the institution ticks, and rather are based on performance indicators, preferably defined under the principles of the rights of persons with disabilities and in view of the promotion of those same rights.

This in turn takes us to an even more specific topic – the topic of quality assessment and quality management, an area that needs urgent developments (7.7). The model of quality assessment in place is still very limited in its ambition and rests primarily on the orientation of each single institution towards the topic, largely determined by the interests and competences of who is managing the organisation. From the regulator’s side, institutions know they will have audits from the social security services, but these will be primarily concerned with the verification of the technical requirements to operate the service and with the compliance with administrative procedures.

Around 10 years ago, there were some developments in this field with the publication, by the Social Security Services, of a series of guidelines concerning the implementation of quality assessment protocols in residential care facilities for persons with disabilities. The planned system was never implemented, and it falls outside the reach of this report to analyse the reasons for that. It was most likely a combination of reasons, ranging from political will to availability of resources to implement it, namely human resources in the social security auditing services. The realisation of the reality of many of the residences operating, for which had the system of quality assessment been used, would not reach the mandatory C level, probably had some influence as well. One cannot forget that having a system of quality assessment in place will generate the obligation to act upon any situation that falls below the minimum threshold.

Resuming this system or revising it to accommodate some additional aspects are both options to consider. What is important to stress is that the sector must have some mandatory system of quality assessment in place. Ideally, the expert would recommend a system that combines service-provider self-assessments with independent quality evaluations. In both cases, it is important that the exercise is inclusive (involving all stakeholders), and that it goes beyond crossing boxes in a list of protocols and procedures to also include indicators of performance and the measurement of outcomes and impacts. In both cases, it is important that the result of the evaluations is transparent and accessible, using adequate formats and language, to all stakeholders, including residents and their relatives. The regulator has the responsibility to lead the way and consult with service-providers, with representatives of persons with disabilities, advocates, and all relevant stakeholders, on the model of quality assessment that is appropriate for the residential care services sector. Resuming the plan of differentiating service providers on the grounds of quality would certainly be a promising project, as it would introduce an element of competition in the social service sector. This sector has traditionally operated as a quasi-monopoly, as the expert discusses elsewhere (Lopes, 2017)[15], and some competition could have positive results for the end-users. An option to be considered for that dissemination of information would be using the existing infrastructure of *Carta Social*, the directory of social care services available in the country. Alongside the information already available in that platform, one could add, for each service, some information about the philosophy of service provision, about the facilities, about the menu of services provided as well as the result of quality assessments, with access to reports and recommendations from independent audits. This would certainly add transparency to the system.

Quality assessment of social care services, however, concerns processes that go beyond the national borders and that may require additional attention from the European Commission's side. Many of the visited institutions had on display the EQUASS Assurance certificate which, in theory, can be used as *"evidence for successful implementation of the UN Convention on the Rights of People with Disabilities"*, as can be read on the website of EQUASS[16]. EQUASS is an initiative of the European Platform for Rehabilitation and is guided by the European Quality Framework for Social Services elaborated by the Social Protection Committee. It is a reputed platform and its evaluations, in some countries, are even used for service provider accountability. The fact that in Portugal the EQUASS certificate is awarded to residential care services that do not meet, by no means, fundamental aspects of rights of persons with disabilities, and that would not even pass on a less demanding exam of quality, is at least puzzling, and offers evidence for the need to revise some of the procedures used in the audits. Further inspection would be required for a full understanding of the quality assessment involved in EQUASS at the national level. It is a subject that the Commission and the Social Protection Committee may want to pursue (7.9).

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[15] Lopes, A. (2017). LTC in Portugal: quasi-privatization of a dual system of care. In Bent Breve (ed.), *Long-Term Care for the Elderly in Europe*, Oxford: Ashgate, 59-74.

[16] See more at https://equass.be/index.php/about-equass

Integration vs. separation of services

One last topic the expert would like to raise under the management and governance models concerns the scope of services that service-providers offer and how these services are articulated (7.8). In most cases, institutions offering residential care services combine them with occupational activities services. This means that for each resident in the care facility the organisation will also gain a client for the CAO/CACI. This is the typical situation of dual billing that may lead to a focus on retaining the client rather than on a project of autonomy and transition to community living. In other words, there seems to be no incentive, quite the contrary, for service providers to address deinstitutionalisation as a personal development project for their residents. If taken to the extreme, one could even ask to same what extent providing institutional care and managing independent living services are compatible if taking place under the organisation.

During the phase of implementation of the pilot projects to test the Model of Support to Independent Living, in place since 2017, the organisations taking the lead were in most cases the same organisations that were managing residential care services. Among the visited institutions, and considering the ones running Independent Living Support Services, in none had any resident of the residential care facility been signalled for transition to Independent Living. The risk of having the same service provider managing both services, services that objectively compete, is that providers will use the services as an adds-on rather than work with services as a menu along the lines of a continuum of support philosophy. It is a topic to consider at the time of evaluation of the pilot projects to decide on the final contours of the system in Portugal (7.8).

Challenges and Opportunities in Residential Care Settings for the Fulfilment of Human Rights: concluding remarks

The purpose of this report was, as stated in the opening, to gather some recommendations that ensure consistency in realisation of rights among persons with disabilities living in residential care settings. The recommendations put forward by the expert of the report were organised into seven dimensions of rights considered of high relevance for residents in institutional care. That organisation stemmed more from the need to offer a clear and easy-to-read layout, rather than from a clear-cut divide across dimensions. If something the expert knows about the realisation of fundamental rights and freedoms is that they tend to have spill-over effects. In other words, the realisation of some rights will always facilitate the realisation of others. That is why there is often some overlapping across dimensions and even across specific recommendations. But it is also why addressing some will most likely facilitate addressing others, and their combined impacts are likely to be bigger than the simple sum of their unique effects. Therefore, the call from the expert is for reading the recommendations jointly and to consider their implementation combining actions on different fronts.

One feature often found in recommendations concerns establishing priorities, an approach that is certainly very appreciated and insightful from the perspective of guiding policy design and implementation, especially if one considers resources are scarce and not all actions can be implemented immediately. When choices need to be made, it helps to establish priorities.

The problem of using that approach in matters of fundamental rights and freedoms is that it would be extremely difficult, if even possible, to argue that some rights and freedoms are more of a priority than others. One could try to develop some rationale around concepts of hierarchy of needs, but that would be ultimately flawed. The argument the expert has been putting forward along the report has been emphasising the need to focus on the individual and to always assess what is more, or less relevant from the perspective of each individual. Doing anything different would be a contradiction.

If looking for some guidance in terms of execution, the expert would recommend a slightly different path and look at how feasible is each recommendation considering the time, the resources, the planning, and coordination it requires for its implementation. Some of the recommendations put forward by the expert offer the potential for a rather quick implementation, especially considering they are under the exclusive control of service providers and require little additional allocation of resources. There are others, however, where the implementation will certainly be more challenging since they will involve more complex planning, the allocation of considerable resources, and the coordination of different stakeholders. From this perspective, one can think about establishing a programme of action guided not necessarily by the relevance of each recommendation for the agenda of fundamental rights and freedoms, but by what can be a reasonable calendar for their execution. Following from here, one can look at recommendations distributed along three stages of implementation: short-term, mid-term, and long-term.

Another angle that can be pursued when trying to establish priorities is consideration of how impactful each recommendation is for the successful implementation of a national policy of deinstitutionalisation. Transition from institutional care to community-based living arrangements is not about closing institutions. It involves a holistic change in how society looks at persons with disabilities and transitioning from an institution to a non-institutional living arrangement is far more complex than changing the postal address. It involves a life project, one where institutions themselves will have a role to play when it comes to their design and execution. The expert has often looked at recommendations in their capacity to induce changes conducive to opportunities for deinstitutionalisation but has also warned that some would be more critical than others in that endeavour. In setting priorities one can also look at recommendations from the perspective of their potential to support deinstitutionalisation.

Setting priorities considering the timeframe of implementation

Recommendations that call for actions that can be quickly implemented are typically those that involve adaptations and adjustments in how daily operations are run at the institutional care facilities and that concern, mostly, aspects of the performance of staff and their interaction with residents, as well as rules and procedures about specific aspects of daily life. These are changes that can be useful not only due to their specific impacts, but also to trigger smaller changes in preparation for more ambitious approaches. They are all feasible in a relatively short window of time, not longer than 6 months, and can all be carried out by the service provider without much need for intervention from third parties.

Among the recommendations that can be followed in the **short-term** and that can be easily followed-up, the expert includes:

- Changes in aspects of the daily life of residents - institutions can introduce some flexibility in how schedules and routine activities are set up, accommodating the preferences of residents, namely in terms of wake-up and sleep times, meals, bathing. This flexibility can also be extended to visitors, both in terms of schedules for visiting times and in terms of their access to the facilities and their participation in aspects of the daily life of residents.
- Tackling low motivation, low satisfaction, and tension among the staff, with particular attention on caregivers - aspects that can be improved immediately include schedules and shifts, and division of tasks among caregivers, towards a more equitable distribution of work and addressing as much as possible family and work balance. While revising schedules and division of tasks, institutions must address the need to always have enough caregivers on-site to decrease risks to residents, especially during the night and at those periods of the day when there are peaks of activity. Relationships between staff with coordination responsibilities and caregivers must be improved, especially with respect to collaborative work and recognition of the value of work secured by caregivers. Assigning caregivers to engage more closely with the monitoring of the progress of residents against IPs can be an interesting way to trigger collaboration while strengthening levels of engagement (and even motivation) of caregivers towards the individual life projects of residents. Institutions should also do a quick assessment of technical skills and provide specific training to any caregiver that lacks training in any specific technical aspects of caregiving.
- Facilitating access to information and communication means - institutions that do not have an Internet signal should install the service and facilitate the access by residents. This will not only facilitate access to information but will also secure access to an important channel of communication and interaction with other people. This can be complemented with the availability of newspapers and magazines in common areas, which the staff can use to raise awareness for aspects of social and political life in the country and the region, and as part of an approach to participation and engagement with the community.
- Engaging residents in activities of daily life and aspects of their own lives – whenever possible and adequate, institutions should involve residents in activities of daily life in the residence, including house chores, as part of training for autonomy rather than confining it to the CAO. Residents should also be stimulated to be more proactive about their health and the pursuit of a healthy lifestyle. Institutions can also work on rights and rights awareness with residents and their families.

These interventions that can be quickly implemented are likely to generate positive reactions among internal stakeholders (staff and residents) and pave the way for more ambitious changes that will require some planning and pooling of resources and that will only be feasible in the **mid-term**. In these group, the expert would include three main domains of action, with a timeline of execution ranging from 1 to 3 years:

- Elaboration and implementation of sector-wide programmes of training targeting the staff working at institutional care settings – although very much needed, training of staff, at all levels, needs to be carefully planned, including preparation of training materials, if to generate initiatives that have lasting impacts. Institutions on their own are unlikely to be able to do it and coordination at the sectoral level would be a smart approach. There will be funding available for sponsoring training programmes under the National Strategy for the Inclusion of Persons with Disabilities, and sectoral representatives, as well as NGOs representing the rights and interests of persons with disabilities, can take a leading role in negotiating with the national authorities an integrated approach to training. They should try to secure, in advance, partnerships with the academia and apply as much as possible innovative formats of training, focused on interactive approaches.

- Integration of residences in the community and facilitating access and inclusion of residents in all aspects of community life – local authorities in articulation, when needed and adequate with national agencies, must secure appropriate conditions of circulation in the surroundings of residential care facilities and must expand routes of public transportation to include them. National authorities should sponsor awareness-raising campaigns about residents in institutional care settings as citizens and active members of the respective communities. Local authorities have a role to play in this as well and should create opportunities for a facilitated presence of persons with disabilities in all spaces and events of the community.

- Investing in networking and exchange of experiences – institutions often operate without knowing much about each other and opportunities to exchange experiences, even across sectors, are rare. Closer collaboration among institutions but particularly among institutions and NGOs focused on advocacy and representation of persons with disabilities should be fostered. Sectoral bodies can be a leading force in this respect, as well as national authorities, bringing parties to the same table and analysing, together, opportunities for collaborative work in promoting and safeguarding fundamental rights and freedoms of those living in institutional care.

Finally, there is a whole group of recommendations that point to more systemic changes and that are likely to take more time to be implemented. They will not only require more in terms of resources, planning, and coordination but they will be especially demanding in terms of political will and resilience, as they are the ones that are more likely to face resistance from a wide array of stakeholders and the ones that will require a more prolonged and consistent plan of action. These systemic changes are only feasible in the **long term**, most likely coinciding with one cycle of national governance (maybe two). They will require national guidance and consistent allocation of funding. On this front, the challenge is mostly about the

- Implementation of a system of regulation of institutional care focused on quality assessment, transparency, rights protection, and social participation of persons with disabilities – this is ultimately about redesigning some of the core principles that have been guiding the social care sector for decades. The national authorities have the leading role in this process and should secure the widest support for this endeavour. Incremental changes that involve all and that are inspired by bottom-up approaches are always preferable. Changes by decree, however, also have a place and disability services in Portugal have experienced some along the years with quite positive results that overcame initial resistances.

Setting priorities considering the potential to support deinstitutionalisation

Emphasis on policies targeting deinstitutionalisation, something embraced as a critical principle in European policy guidelines in what concerns the place of persons with disabilities in society, cannot be done dismissing the institutional care sector as if it has nothing to do with it. On the contrary, and as the expert sees it, deinstitutionalisation starts at the institution. Deinstitutionalisation is not simply about changing the address where the person lives. And it certainly is not just about closing down institutions as if transition to community-based living arrangements is something individuals can do over night. It is important to keep in mind that for many of those living in institutional care, the institution has been the place of residence they have known for decades (some residents in the visited institutions had been living there since late childhood and some for more than two decades). Changes need to start at the institutional level, namely because individuals need to prepare themselves to a new project of life, activating or reactivating skills and competences that will be critical for a successful transition from the institution. Experiences of deinstitutionalisation projects in several countries have already provided enough evidence that if the process of deinstitutionalisation itself is not properly supported, individuals may end up being thrown to a situation of social exclusion that will be, if not worse, at least as bad as living in an institution from the perspective of their fundamental rights and freedoms.

Along the presentation of recommendations, the expert has tried to draw the attention of the reader for the implications of some in terms of their potential to successfully support deinstitutionalisation. In a summarised and more systematic manner, those recommendations are the following:

- Training staff, at all levels, on person-centred and rights-based models of support with a focus on promotion of autonomy. Relationships of care are the ones typically found inside institutional settings and they have their toll on the residents' side in terms of consolidation of a social role that persons with disabilities will learn to play themselves the longer they remain institutionalised. If deinstitutionalisation represents a major paradigm shift for society as a whole, it certainly represents a major shift for all those that have lived all their adult lives inside an institution. Training of staff is fundamental to allow both staff and residents to move from a relationship of care to one of support, empowering residents and capacitating them to be more in charge of their lives, paving the way to a successful transition from the institution. Additionally, this will help build the necessary skills that will be required in terms of professionals engaged in community-based services. Although we tend to think about deinstitutionalisation primarily thinking about persons with disabilities, it can also be put from the perspective of staff. They will also transition into new types of jobs as the institutional care sector decreases and training is a good approach to assist in that transition of the labour force.

- Facilitating participation in the community while still at the institution is another area where several of the recommendations can be grouped. This has to do with the social connectedness that will be critical for a life project that does not involve the institutional care setting: accessibilities, access to information, access to the Internet, availability of assistive devices, access to instances of representation. These are all fundamental aspects in preparation to a fuller integration in the community of persons with disabilities currently residing in institutions and need to be already worked while at the institution, in a supportive environment, so that chances of successful transition increase.

- Organising activities to empower residents in institutional care, activating skills and capabilities that institutional cultures tend to weaken. Supporting projects that can be developed by NGOs representing persons with disabilities, advocacy agents and other organisations of the civil society offers a very high potential in preparation for more autonomous models of living arrangements. Deinstitutionalisation is about exercising rights and exercise of rights starts with raising awareness for one's rights and empowering individuals, with knowledge, information, tools, and resources to be active agents in the safeguard of their rights.

- Adapting national regulatory frameworks to include in individual plans of development of residents, aspects related with deinstitutionalisation, with a mandatory character. This would send a clear sign to all stakeholders that institutionalisation should not be regarded as a life plan and a fundamental step forward to embed both technical staff with coordinating responsibilities working in the sector and public officials in charge of regulatory tasks in a culture of rights rather than in a culture of institutional care.

- Integration of healthcare aspects in service delivery namely in what concerns mental healthcare. The coexistence of disability and mental illness is far too frequent among residents in institutional care settings. Access to appropriate healthcare is fundamental to ground projects of deinstitutionalisation for those residents.

- Foster engagement in skills formation among residents with a view on integration in the regular labour market or in protected employment. This is a crucial aspect of life in the community (the ability to generate one's income) and may very well be the crucial step for many residents currently living in institutions to be able to transition to community-based living arrangements. With the change of CAOs into CACIs it is very important to guarantee those living in institutions will not be left out and that eligibility criteria will not hurt their fair chances of pursuing training and skills formation to integrate some form of paid work.

A core element of living independently and being included in the community is that all persons with disabilities have the support they may require to carry out daily activities and participate in society, based on their choices and life projects. Support should be individualised, personalized, and offered through a variety of options. Support encompasses a wide range of formal assistance, as well as informal community-based networks. The Portuguese landscape is still severely biased towards institutional care (and family care) and quite underdeveloped in what concerns alternative forms of support that promote and facilitate independent living in the community. As it is at present, there are very strong reasons to believe that the existing capacity is insufficient to tackle the needs of those living in the community. Deinstitutionalisation of those currently living in institutional care facilities will further aggravate the pressure on community-based arrangements and it is unlikely to succeed if there is no significant expansion of such arrangements. At present all signs point to a continuing investment on expansion of institutional care. If that continues to be the dominant policy choice, then all contents and recommendations included in this report are unfeasible.

If and when deinstitutionalisation if fully embraced as a policy path in Portugal, then issues of how it is to be implemented and achieved will gain relevance. Deinstitutionalisation is a challenging domain that requires articulation, coordination, and resilience (as well as adequate funding) of a myriad of social actors that need to be involved and invested in securing everything it takes for a person with disabilities to successfully transitioning from institutional life to living independently in the community. Part of the efforts that need to be put in place concern institutions themselves and the role they must play in helping residents prepare for life in the community. In this report the expert has highlighted aspects of the current modes of operation of Portuguese institutions that need to be changed and improved if they are to be involved as active players in the implementation of deinstitutionalisation efforts. Although one agrees that funding institutions in view of perpetuating institutional care is not acceptable, some funding may be required to create the conditions, at the institutions level, to facilitate and increase the chances of success of deinstitutionalisation. The recommendations put forward by the expert are outlined under this rationale and must be read as part of the global efforts to push forward the agenda of deinstitutionalisation in the country.

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