Trinity College Dublin
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Trinity Centre for Ageing and Intellectual Disability

Daughters of Charity Disability Support Services

The experience and risk of homelessness for people with intellectual disabilities and/or autism and their families in Dublin. A mixed methods study.

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November 2020

Údarás Náisiúnta Míchumais
National Disability Authority

Acknowledgements

This study would not have been possible without the participation of those people at the very centre of the issue – families and individuals (either supporting someone with a disability or having a disability themselves) who have lived experiences of homelessness. They participated openly, were generous with their time, and have given us a real insight into what their experiences have been. We are very grateful to them for taking part.

The Gatekeepers for this study, The Daughters of Charity Disability Support Services (DOCDSS), facilitated every aspect of the research, often under difficult working circumstances during the COVID-19 pandemic. Their input has been invaluable, both in qualitative and quantitative terms.

Ms Kathyan Kelly, research assistant to the project, has been pivotal in realising the ambition and vision of TCD researchers and Daughters of Charity Disability Support Services staff, to give voice to people and their families with ID and/or ASD who have experienced homelessness and to shed light on a systemic issue that many people with ID and/or ASD are likely experiencing or at risk of experiencing nationally. We thank you for your dedication, hard-work and empathy throughout this study.

We wish to thank the National Disability Authority for providing funding for this research project.

We would also like to thank the Scientific Advisory Committee for their support, advice and feedback during the research. The Committee comprised:

- Ms Patricia Cleary, HAIL Housing Association
- Dr Christine Linehan, UCD
- Prof Mary McCarron, TCD
- Prof Philip McCallion, TCD / Temple University

Special thanks also go to Michael Foley, Research and Development Officer, Trinity Centre for Ageing and Intellectual Disability (TCAID).

Funding

The National Disability Authority has funded this research. Responsibility for the research (including any errors or omissions) remains with the Researcher/ Research Team. The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of the National Disability Authority.

Table of contents

List of tables and diagrams

Glossary of terms used

AHB	Approved Housing Body
B&B	Bed and Breakfast
CAS	Capital Assistance Scheme
DPIA	Data Protection Impact Assessment
DPO	Data Protection Officer
DOCDSS	Daughters of Charity Disability Support Services
DPHLG	Department of Planning Housing and Local Government
ECRS	Electronic Client Record System
EPAP	European Platform Against Poverty
EU	European Union
ETHOS	European Typology of Homelessness and Housing Exclusion
EIDRN	European Intellectual Disability Research Network
FEANSTA	European Federation of National Organisations working with the Homeless
GDPR	General Data Protection Regulation
HSE	Health Service Executive
HAP	Housing Assistance Payment (formerly RAS)
IDS-TILDA	The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IPRT	Irish Penal Reform Trust
NASS	National Ability Supports System
NDA	National Disability Authority
NIDD	National Intellectual Disability Database (now NASS)
NHSPWD	National Housing Strategy for People with a Disability
NGO	Non-Governmental Organisation

PEA	Private Emergency Accommodation
RA	Research Assistant
RAS	Rent Allowance Scheme
SIP	Social Investment Package
SRV	Social Role Valorisation
TCD	Trinity College Dublin
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Note on the use of the term 'Service User'

It is our understanding that the term 'Service User' is one that both families and individuals interacting with DOCDSS would like to see changed. However, in the absence of an alternative term that is currently widely accepted and understood, we have continued its use throughout this report.

‘My son’s behaviour became something else. He was a child I did not know. I was staying out the whole day. Every morning I have to get up and go [out] and then my son - he is crying to go home – so we are running to go to the home where we have lived just to show him that we can’t – that it is closed – that was something we were doing every day. I would have to go and show him and let him understand that we can’t go back to the house then we go to the park and then we go round, round, round.’
[Nadia, Mother aged late-40s describing trying to manage her young sons’ distress, who has ID and/or ASD, following eviction and subsequent homelessness].

Executive summary

Aims and research methods

This research is a small mixed methods study that explores the experiences of people with ID and/or ASD experiencing homelessness or homelessness risk. It uses a single Service Provider in Dublin, the Daughters of Charity Disability Support Services (DOCDSS) and elicits views of staff, and service users and their families.

Housing is identified as an important non-medical determinant of health. Health and future health outcomes of an individual are directly impacted by the conditions of their daily life and the resources available to them. Beyond the rights-based framework that testifies housing as a human right, access to quality, stable housing directly impacts on health outcomes and its absence increases pressure on health systems.

There have been moves to improve the lives of people with ID and/or ASD, most notably by Ireland following United Nations policy on de-congregation Ireland ratified the United Nations Convention on Rights for People with Disabilities in 2018, which states that people with disabilities should have choices equal to others so that individuals have the option to choose where they live, and with whom as well as having the supports needed for inclusion in the community.

The classification of living situations that comprise the experience of being homeless used in this study is that of the European Typology of Homelessness and Housing Exclusion (ETHOS) and includes not just being roofless, but also living in a situation of insecure tenancy, inadequate and inappropriate housing in that it fails to meet the needs of the people living there. The use of this classification is of particular relevance to the people who participated in the study. This definition also includes incipient homelessness, where a living situation cannot be maintained due to threat of eviction or violence or where people are living temporarily with family or friends which may not be sustainable leading ultimately to homelessness.

Estimating the number of individuals with ID and/or ASD living homeless is not yet possible in an Irish context. There is an acknowledged invisibility of ID and ASD due to high levels of non-diagnosis and limited supports. However, the experiences and perspectives of front-line staff, working in both the disability and homeless sector, attest to the fact that this group are experiencing homelessness. Research in this area is limited yet emerging and this research can be seen primarily as a test bed for further examination into an issue driven by practice insights within the DOCDSS.

In the absence of these national statistics this research aims to explore those experiences through the direct narrative of people with ID and/or ASD, and families who have a relative with ID and/or ASD. This allowed us to gain insight into their reality of homelessness and homelessness risk and in doing so, to explore how they perceived and understood those experiences. As a small case study, it sought the views of four Service Users and five family members within the DOCDSS and Staff Members who are working directly with Service Users, providing a qualitative overview. The study also utilised a comprehensive literature search as well as the use of quantitative data provided by the DOCDSS. As a small sample it does, however, have limitations and provides a limited number of ethnic and cultural experiences.

Specifically, the research questions aimed to explore issues around homelessness as experienced by individuals and families and encountered by social workers in the service, namely:

- The interplay of socio-economic, cultural and ethnic issues leading to a risk of homelessness
- The factors leading to the participants in this study being adequately housed, homeless or at risk of homelessness
- The challenges to participants with ID and/or ASD to access stable housing options
- The factors which lead adults with ID and/or ASD in this study returning to residential services if housing is unavailable or breaks down.

Data collection

Data collection was both qualitative and quantitative. The qualitative element involved five Family Service Users and four Individual Service Users.

Interviews were conducted by phone with open-ended questions that were compiled based on the findings of a literature review. Participants were asked of their experiences of the housing market, as well as their housing history. Sociodemographic characteristics were also collected. Quantitative data was provided by the Electronic Client Record System of the DOCDSS to provide a socio-demographic profile of Service Users. Additionally, Staff Members provided additional statistics (based on their individual caseloads) who were homeless or at risk of homelessness.

All data was gathered in the period March to June 2020. Due to Covid-19 restrictions at the time, interviews were carried out by phone, and written reflections were emailed by Staff Members.

Participant profile

A full participant profile is presented in Chapter 3.0. Six Staff Members within the DOCDSS were asked to give their views on housing and homelessness for people with ID and/or ASD. They gave this in the form of a written reflection using an open-ended questionnaire.

Five family members were recruited to the study, one male and four female. Except for one participant (who was responsible for her sibling's care) they were all parents to children (or adult children) with ID and/or ASD.

Either they as a family, or the person they were caring for, had moved between two and eight times, with an average of four moves and had spent between one and four years homeless. These moves ranged from home to acute hospital, private rented to emergency accommodation (Hotel, Hostel, Family Hub).

Four individual Service Users participated in the study. This group had moved accommodation between one and eight times, with an average of 4.5 moves and had spent between one and two years homeless. These moves ranged from home to community residential houses, respite and private rented as well as supported congregated settings.

Results

Quantitative results

Service user housing

Of 1,130 Service Users availing of services from DOCDSS in the Dublin and Greater Dublin/Leinster area, 51.6% (n=584) were male and 52.2% (n=590) were aged 18+ years.

Of those aged under 18 years of age 47.8% (n=540), three quarters (75.6%) were living at home with both parents while 16.9% were living at home with one parent.

A much lower percentage of those aged over 18 were living at home with both parents (21.9%), or one parent (12.9%). The most prevalent type of residence reported was a residential centre (36.1%) and a residential community house (25.4%). A small percentage were living independently or semi-independently with their peers with supports (2.7%).

The DOCDSS had been de-congregating since 1991 and opened twenty-three purpose-built bungalows to accommodate 167 residents. However, as these houses are not in the community, they are not considered to be part of the overall de-congregation strategy and are not enumerated in the HSE statistics. Moves from a congregated setting to community over 2016 and 2018 numbered thirteen, and delays because of COVID-19 temporarily halted the planned move of three residents for this year, with a further three planned for 2021.

The current vision for housing for DOCDSS is through Marillac Housing Association, now established as a separate Approved Housing Body (AHB) to the organisation which will enable the sourcing of person-centred housing through a variety of linked housing bodies and funding.

Homeless/homeless risk profile

Work was undertaken by the Social Work team to compile data on individuals and/or families in their caseloads over the past ten years that met the definition of homelessness/homelessness risk guiding the study.

This resulted in (n=145) individuals/families identified as homeless or at risk of homelessness with 31 of this group reported as crisis admission to the DOCSSS services, a nursing home or a hospital but effectively homeless.

Most of the crisis admission group were over 18 years of age (90.3%), whereas the age profile of the homeless non-crisis group saw a more even spread (54.4% aged 18 and over).

Moderate and severe/profound were the highest report levels of ID across both groups, with the majority recording a secondary diagnosis (ASD, physical disability or other chronic health condition).

Those who presented as crisis admissions were more likely to come from one parent families (67.8%) where those in the non-crisis group were more likely to come from a two-parent family.

Those in crisis admission were less likely to report being on the wait list for social housing (n=4) while 45 people (39.5%) of the general homeless category were on the waiting list, with the greatest proportion (12.3%) on the list for between eight and ten years. The average wait for housing in the general population is seven years.

Respite

Typical allocation of respite is one day per month per person. However, not everyone avails of or is entitled to respite, and individuals and/or families must apply for the service. Of the 145 people on the homeless/risk of homeless list, just 49 had availed of respite services. Of these 49 people, the number of nights in one year ranged from 1 to 365 with an average number of respite nights of 46.9 nights. However, one individual was in respite placement for 365 days which equates to an emergency/crisis placement and so could be seen to distort the average. With this removed, the average respite days for Service Users is 12. The age of those receiving respite ranged from 7 to 67 years, with the average age 28 years.

Factors leading to homelessness risk

Staff most frequently reported threats to homelessness as issues with the landlord (21.9%) the demands of caring (20.2%) and the house not adapted for disability (12.3%).

The reasons motivating crisis admissions were also recorded based on staff observations and experience.

The most dominant reason for crisis admission is the inability of the carer to continue with the demands of caring (45.2%) and the ill-health of the parent or carer (25.8%).

Qualitative findings

The diagram below provides a summary of the qualitative findings. It includes the six Staff Members written reflections, as well as the five families who use their services and four individual Service Users of the DOCDSS.

A summary of qualitative findings from all participants

Staff Findings	Family Findings	Service User Findings
•Socioeconomic, cultural and ethnic issues •poverty and economic dependence •cultural and ethnic issues •age and gender •family size •education and literacy	**•Socioeconomic, cultural and ethnic issues** •poverty and economic dependence •cultural and ethnic issues •age and gender •family size •education and literacy	**•Socioeconomic, cultural and ethnic issues** •economic dependence •age and gender •education and literacy
•Inadequate Housing •sub-standard accommodation •practical difficulties •the need for physical space •crisis admission •children and residential services •lack of independence •temporary housing	**•Inadequate Housing** •dependence on private rental market •emergency accommodation •care crisis •regression and behavioural changes •psychological ill health and homelessness	**•Inadequate Housing** •dependence on private rental market •emergency accommodation •care crisis •pyscholological ill health and homelessness
•Housing Instability •lack of security of tenure •absence of services •behavioural issues •changing needs •the implications of instabilty	**•Housing Instability** •lack of supports •control, choice and coercion •practical issues •behavioural issues •changing needs •marginalisation	**•Housing Instability/Return to Residential Services** •lack of support •choice and control •number of transitions •behavioural issues •lack of social connectedness
•Return to Residential Services •over-reliance on private rented sector •bureaucracy •marginalisation •lack of individualised supports	**•What is a home?** •safe space •basic human right	**•What is a home?** •proximity to services •social network •independence

Participants across all groups cited socioeconomic factors around entering a state of homelessness, most notably an over-reliance on social welfare as a driver for this as well as poor literacy.

Inadequate housing is driven by an over-reliance on the private rental market for accommodation, which, due to a lack of understanding of the needs of people with ID and/or ASD leads to substandard accommodation (including emergency accommodation) and subsequent health issues.

As a result of this dependence on the private rental market, there is little in the way of security of tenure, leading to housing instability which is further compounded by lack of supports, the changing needs of families as well as behavioural issues which lead to marginalisation.

There is clear evidence that the return to residential services is predominantly driven by over-reliance on private rental accommodation, as well as the difficulty accessing housing (through bureaucracy), marginalisation and a lack of individualised supports.

Study Limitations

It should be noted that this study had a number of limitations. Due to its small sample size and the fact that it used data from one Service Provider in the Dublin area, it cannot be said to be generalisable at a national level. Data gathering for the study took place during the COVID-19 pandemic, which meant that face-to-face interviews could not take place. While every effort was made to establish contact via video call (What's App) prior to interview, it should be noted that visual cues were not available to the Research Assistant. Also worthy of note is the fact that because phone interviews were conducted, this meant that only people with a mild or moderate ID and/or ASD could be interviewed and people with more profound communication challenges were omitted.

Conclusion

This study has not provided a critique of existing housing policy in Ireland nor a review of the success or otherwise of any programme efforts, especially in the absence of specific policy addressing the idiosyncratic needs of people with ID and/or ASD. In particular, there is no policy on the housing needs of adult children living with parents, or families with children who have ASD and live in inappropriate settings. However, there are a number of issues that have been raised that require attention. This study finds that, in the absence of sufficient appropriate social housing, reliance on the private rental market in its current form is not feasible for a group of persons with disabilities and their families who, as outlined in this study, are already facing poverty, economic dependence and social marginalisation.

Emergency accommodation, in its present form, is not suitable or appropriate for most families, but is especially challenging for families who have a child with ID and/or ASD with a possible attendant physical disability. Placement of a family in one room with limited facilities has led to reports in this study of severe psychological difficulties in carers and behavioural and developmental regression in children.

Using the classification of homelessness guiding this study families find themselves, even in non-emergency accommodation, in inappropriate housing. The use of the FEANSTA classification (as opposed to less inclusive legislative Irish one) meant that the study has particular relevance for this cohort. Examples in this study include those who have limited space, which restricts movement; lack of outside space (essential for children with ID and/or ASD); in houses where bedrooms and bathrooms are upstairs where there is a child with ID and/or ASD and attendant physical disability as well as general living conditions which are not conducive to good health (such as damp/fungus on walls).

These families, similar to many families who do not have a person with a disability as a member, also experience housing instability brought on by an over-dependence on the private rental market which leaves them open to market forces where they often find that rent costs are out of their reach and that there is an unwillingness for landlords to accept Housing Assistance Payment (HAP) tenants.

Inappropriate and unstable housing is also a factor in this study for older adults with ID and/or ASD living with ageing carers. They do not have the social, cultural and economic resources of their non-disabled peers (due to lower education and employment possibilities) and so find themselves at a distinct disadvantage when trying to navigate the housing market independently.

For adults with ID and/or ASD who are living at home cared for by parents or siblings, there is evidence in this study to suggest that they experience similar issues, with particular difficulty accessing the social housing lists, either because they are not encouraged to do so by their carers or because according to social workers in this study they are not viewed as a priority on the social housing list. Most Local Authorities give priority to those longest on the waiting list as well as those with identified medical need. In addition, there are a number of specific housing categories – older person (over 55 years) accommodation, homeless persons and traveller specific accommodation.

Inappropriate housing is also experienced by individuals in this study who were placed long-term in acute medical settings, respite or who returned to congregated settings for long periods of time. Some participants said this led to psychological distress both for themselves as individuals and for their family members.

While there is a policy on disability and housing, it focusses on those with a physical disability in the main and those who are ageing. There is no specific policy that meets the needs of children and their families in gaining and attaining suitable and appropriate housing within the ID and/or ASD cohort.

The DOCDSS as a Support Service employs innovative practices to work in partnership with people with disabilities to empower them to live the most independent life possible, using best practices. However, this study shows that these innovative practices have been hampered by lack of funding and poor statutory agency approaches at a national level. For example, moves towards independent living in the private rental market were not sustainable due to insecure tenancy.

It is clear from this study that there is a greater need for an inter-agency or inter-sectoral approach to the issue of people with disabilities experiencing homelessness. Housing, and lack of housing is a non-medical determinant of health and as such, inequalities in health can be linked to disadvantages in other areas. Responsibility for addressing this issue lies across different statutory agencies.

Participants in this study described experiences that pointed to a lack of inter-sectoral support. Housing comes under the remit of a number of Government departments and other agencies, while disability services are the responsibility of the HSE. Families and staff report poor understanding of the need for physical space in homes as well as difficulty accessing funding for essential adaptations. There is evidence of families and individuals being given little or no time to accept housing offers, or being offered housing that is unsuitable for their needs. This suggests a gap in knowledge sharing between those responsible for housing and those responsible for disability services.

As suggested in other research, a life course approach could be implemented which would account for early negative life events (disability, homelessness, lack of access to education, poor supports) which impact greatly on later health outcomes.

There is also a considerable need for communities to become engaged in both supporting, and understanding, the needs of people with ID and/or ASD.

Homelessness is not solved purely by the provision of a roof over someone's head. In order for individuals and families with ID and/or ASD to not only survive, but to thrive, there needs to be an individualised, well-funded person centred support plan that is put in place at an early stage (before a family or individual becomes homeless) and has the capacity to adjust to changing needs over the life course of the individual.

Recommendations

While the findings of this study are not generalizable due to their small sample size insights were gained into the lived experience of people and families with ID and/or ASD experiencing or being at risk of homelessness. The recommendations draw on ways to improve/prevent these experiences. Many recommendations may also be of benefit to other vulnerable groups in that they call for both a review of existing policy and suggest the implementation of preventive strategies. Based on the quantitative results and qualitative findings, recommendations are presented at an overarching and service level. The first are recommendations specifically for housing policy for people with intellectual disability and/or autism, while separately recommendations for the DOCDSS are made.

Overarching recommendations

With regard to Housing Policy in relation to people with ID and/or ASD, it is recommended that:

- A specific Housing Policy for People and Families with ID and/or ASD framed by a life-course and human rights perspective is established.
    - It should acknowledge that adults with ID and/or ASD living with parents but wishing to live independently need to be facilitated.
    - The policy is adequately resourced

  - The social worker observations in this study outlined a number of barriers for persons with ID and/or ASD in accessing the housing market. They recommended a review of Social Housing/Private Rental Market is undertaken and focuses on the following issue.
    - Reducing bureaucracy in applications for housing and accessing HAP payment: streamline/simplify access by provision of accessible materials

Specific gaps in education and engagement in the housing sector were identified and as such it is recommended that there is a need for:

- Establishing a forum for cross-sectoral collaboration
- Increasing awareness of the needs of people with ID and/or ASD across Statutory and Housing and Disability Services as well as for landlords operating in the private rental market, through education and incentives (such as financial incentives to provide adaptations)
- Revising income thresholds for eligibility in local authority housing for people with ID and/or ASD and their families
- Providing greater protection from eviction
- Identification of the prevalence of homelessness/risk of homelessness on a national level of people with ID and/or ASD to allow for appropriate responses and future planning
- Engagement of communities, Staff and Service Users in participatory dialogue to promote care in the community

Recommendations for DOCDSS

The DOCDSS provided a useful case study location for exploring the issues of homelessness and risk of homelessness for people with ID and/or ASD and their families in a capital city. While this study is not generalisable to the general population it is likely that other disability services are no doubt encountering similar challenges to supporting this group in obtaining sustainable, safe, secure and appropriate housing and may benefit hugely from the insights provided by DOCDSS and their Service Users in this study. There are also specific recommendations that DOCDSS may wish to consider to support their future planning and development of innovative and person centred supports for their service users.

- To inform and enhance planning the service could
  - Expand the current database review to ensure that information gathered can generate best evidence to highlight need, for example, including age of carer
  - Identify at the earliest stage families and individuals most at risk of homelessness/housing instability, for example, expanding definition of homelessness in line with the European definition and staff observations

  - Continue implementation of the new AHB status (Marilliac Housing Association) as a specific service driven initiative to address the multi-faceted issue of homelessness
- Consultation should continue to inform DOCDSS practice ensuring that
  - Individuals and families continue to be fully engaged in choice around their home
- Information sharing should continue and develop
  - Seek to share information, generate discussion and identify specific strategies with staff, families, service users as well as local authorities involved in housing and Statutory Agencies responsible for the issues (DHPLG, DOH, HSE, DSP).

Future research

- As this research was conducted during COVID-19 restrictions, it was limited to the experiences of Service Users with mild to moderate ID and/or ASD. Future research should include the voice of those with more profound levels of disability.
- Review income level caps for adaptation grants or follow the Danish model and based on need not income
- Recognising that emergency accommodation is in no way desirable, the current options are even less suitable for people with ID and/or ASD. As such, suitable alternatives to emergency accommodation are required which would allow for earlier intervention with additional financial supports to enable them to stay in their accommodation or quickly find new accommodation. Specific research is needed as to what this could look like and how this would work in practice.
- New and innovative models of housing for people with ID and/or ASD which prioritise independent living options with supports as required and individual choice need to be examined and explored. Some examples of innovative models have been identified in the literature in Denmark, Australia and Canada but further evidence is needed on these models including how they would suit the Irish context
- An advice paper on achieving Universal Design in new housing was presented by the NDA to the Department of Planning, Housing and Local Government and is currently under consideration (NDA 2019). This should be revisited with a view to establishing requirements for Universal Design in new builds

Introduction

This research is a small mixed methods study which explores the experiences of people with a disability experiencing homelessness. In utilising a single Service Provider in Dublin City (Daughters of Charity Disability Support Services - DOCDSS), it focusses on the people, and families of people, with an Intellectual Disability (ID) and/or Autism Spectrum Disorder (ASD) as well as those who support them. Definitions of ID and ASD are contained in Appendix 1.

It aims to explore issues around homelessness and homelessness risk for individuals with ID and/or ASD, and families who have a member who has an ID and/or ASD. The classification of homelessness used in the study is that of the broad European definition by FEANSTA and includes people who are living in inappropriate or unsuitable accommodation as opposed to those who are just without a home. The definition of homelessness is outlined more fully in Appendix 1.

The study specifically aimed to look at issues around homelessness and homelessness risk for this group, namely:

- The interplay of socio-economic, cultural and ethnic issues in leading to risk of homelessness
- The factors leading to this group being inadequately housed, homeless or at risk of homelessness
- The challenges to people with ID and/or ASD to stable housing options
- The factors which lead adults with ID and/or ASD returning to residential services if housing is unavailable or breaks down.

In using a case study approach, this study has limitations in terms of generalisability to the greater population of people with ID and/or ASD. However, in the absence of statistical data on homelessness/homelessness risk for this population, it serves as a starting point for further research.

There are two elements to the study – qualitative and quantitative data. The qualitative data was gathered in the form of interviews and written reflections. However, the study was carried out during the COVID-19 Pandemic, which placed barriers to participation by individuals for qualitative interviews. Their views on the effects of the early stages of the COVID-19 restrictions are presented in Appendix 2.

The first chapter is an overview of housing and homelessness policy in Ireland and elsewhere and looks at the factors leading to homelessness in the general population, as well as an examination of factors that are specific to people with ID and/or ASD.

The second chapter explains briefly how the research was carried out and the rationale for the methods utilised to answer the research questions. The third chapter provides an overview of the research participants.

The fourth chapter presents the findings from the quantitative analysis of the DOCDSS client database, while the fifth chapter presents the qualitative element of the study. This comprises analysis of written reflections of Staff Members working within DOCDSS as well as from interviews with family and individual Service Users who have, or are caring for, someone with ID and/or ASD.

The sixth chapter discusses these findings in the context of current literature and follows with a concluding chapter and recommendations based on the analysis, while the final chapter concludes the research and lists some recommendations.

1.0 Literature review

1.1 Introduction

This chapter gives a brief overview of International, European and Irish academic literature policy on housing for people with ID (Intellectual Disability) and/or ASD (Autism Spectrum Disorder).

Due to the limited (though emerging) research to date in the specific field of homelessness and intellectual disability, the main structural and personal pathways into homelessness within a general population as well as those pathways specific to people with ID and/or ASD and their families are explored. The chapter also examines the specific social issues affecting this group that impacts on their ability to attain and secure housing, particularly around the notion of housing as a social determinant of health.

In doing so, this chapter aims to establish the main themes that relate to the research question which is an examination of the experiences of people with ID and/or ASD and their families around homelessness. It concludes by outlining some options for exiting homelessness based on international research for this group.

The following terms and sources were accessed for this section.

1.1.1 Search terms:

- Intellectual Disability, Learning Disability, Cognitive Disability, Developmental Disability, ASD/Autism, Disability, Social Inclusion.
- Homelessness, Housing Rights, Houselessness, Health.
- De-congregation, de-institutionalisation.

1.1.2 Literature review scope and sources:

- Cochrane, EBSCO, ERIC, Medline, PsychInfo, PubMed, Scopus, Web of Science.

1.1.3 For policy:

- Google and Bing Search Engines – International, European, Irish policy on: Intellectual disability, disability, homelessness, families, social housing, social inclusion.

A single Service Provider, the Daughters of Charity, was utilised to provide access to the perspectives of staff, individual and family service users in order to address the research question. The Daughters of Charity, since its foundation over a century ago, has developed and adapted in response to the changing needs and circumstances of people with ID and/or ASD. These supports are provided in residential and day services, community houses and in enterprise and employment services and cater for people throughout the life course from birth to old age.

It currently operates forty houses in Dublin that give care and support to those with an ID and/or ASD, as well as the provision of other support services around housing in the community and social inclusion. The Daughters of Charity had previously acted as an Approved Housing Body (AHB) and received funding for the provision of accommodation and recent regulatory changes have separated that provision into a distinct entity. The establishment of the Marillac Housing Association (which is a separate legal entity) allows the organisation to work in close conjunction with, but separate to Marillac, the Approved Housing Body, enabling both the provision of appropriate housing for their target group as well as developing alternative models of housing. This allows for future planning working directly with the Department of Housing, Planning and Local Government (DHPLG) and local authorities.

The section of Daughters of Charity which facilitated this study is the Daughters of Charity Disability Support Service (DOCDSS), which employs staff members working across a range of services aimed at improving the lives of people with ID and/or ASD. Their practice is based on interventions using a systematic body of evidence-based knowledge and practice with an emphasis on Social Role Valorisation. (Osburn 2006)

1.2 Intellectual disability and 'labelling'

Definitions and labels are in constant flux with often little consistency within and across countries in the terminology used and the criteria applied to meet a particular definition. This not only creates challenges in terms of reporting and comparing statistics on people with disabilities, but also has real impact on the eligibility of people with disabilities to specific services and supports. Historically and culturally terms to describe persons who experience intellectual disability have changed. The label 'person with an intellectual disability' is not one recognised by the World Health Organisation as it is an administrative rather than a bio-medical label which encompasses a vast range of abilities (World Health Organisation 2018). The provision of the label 'intellectual disability' may well do an individual a disservice, laden with stigma as it is, and it has been noted that it can sometimes be 'a passport to poorer living conditions.' Since the category 'intellectual disability' is a social construction, it can be unhelpful as the population of people with intellectual disabilities includes people with quite different needs and wants. As such, service systems must be responsive to people's differences at various levels – individually, clinically, socially and as part of their wider community (EIRDN 2003).

Equally, not applying a label may be unhelpful in that it leaves people vulnerable to market forces and to being left behind in the competition for scarce resources without advocacy as a group. The answer would appear to lie somewhere between making everything accessible to all groups regardless of ability and tailoring a one-to-one approach for each individual who has the label 'intellectual disability.' This is of relevance where the disability is so profound that universal accessibility would be of limited help, and that the person would continue to need help, support and advocacy. Developments in definitions and classifications of intellectual disability (Schalock, Luckasson and Shogren 2007; World Health Organisation 2001) suggest that assessment provides for a plan to allow the individual to be able to function in the way that they wish (EIDRN 2003).

There is a high level of co-morbidity between people presenting with both intellectual disability (ID) and Autism Spectrum Disorder (ASD). The latter is defined as 'persistent deficits in social communication and social interaction across multiple contexts' manifested by deficits in social-emotional reciprocity, nonverbal communication and relationships (American Psychiatric Association 2013)

Given this high level of co-morbidity, this study uses the term ID and/or ASD throughout (Ozerk 2018; Srivastava and Schwartz 2015).

1.3 ID and/or ASD and co-morbidity

There is evidence of an increase in ASD internationally and that this may be due to changes in diagnostic criteria or an increased recognition of the pathology (Ozerk 2018). Of those with ASD, 70% co-present with an intellectual disability (the remaining 30% present with speech and/or behaviour problems). Conversely, at least 10% of people with an intellectual disability co-present with ASD (Srivastava and Schwartz 2015).

Individuals with ASD and/or ID experience higher levels of psychopathology (anxiety and depression) than the general population, with mental health problems recorded in 60% of an older population with ID and/or ASD (Mulryan et al 2014). For those with both ASD and ID, there is also a greater degree of hyperactivity, distractibility and impulsivity (Matthews, Bell and Mirfin-Veitch 2018).

Furthermore, recent research suggests that individuals with ID experience much higher levels of 'multi-morbidity' (two or more attendant physical and/or mental health conditions) than the general population (Cooper et al 2015).

Irish statistics suggest that 35% of people on the National Intellectual Disability Database [NIDD - now NASS, the National Ability Supports System] experienced both an Intellectual Disability as well as an attendant physical or sensory disorder (Health Research Board 2010).

For individuals with Autism and their families there is a link between ASD and poor socio-economic outcomes. 'Social vulnerability, unemployment, and difficulty interacting with services can be catalysts for homelessness, compounded by lack of diagnosis and appropriate support. Prevalence rates are difficult to determine for individuals with Autism in a homeless population.' (Stone 2018).

A recent study in Australia examined the needs of families living with children with ASD in their homes and found that there were several idiosyncratic needs for children and parents looking after their children with ASD (Cocks et al 2017; Fisher et al 2008). These findings led to recognition of a need to broaden the base for acquiring resources for such families and to ensure that housing modifications encompass a broad spectrum of needs including diverse sensory-perceptual worlds (Glasgow City Council 2018; Owen and McCann 2018).

1.4 Homelessness and housing policy

1.4.1 Homelessness and housing policy in an international context

Housing as a basic human right, provides dignity, physical and mental health as well as quality of life and security (United Nations 1948; 1991; 2019). The United Nations has clarified governmental obligations in declaring the right to adequate housing as a basic human right (United Nations 2009). As a human right, adequate housing encompasses all that is necessary to provide an adequate standard of living, legal security of tenure as well as the provision of habitable, accessible and adequate housing resources, with a need for priority consideration for vulnerable groups such as those living with ID and/or ASD (United Nations 2009).

As part of ensuring these rights for vulnerable groups, a specific article (Article 19) was included in the 2006 UNCRPD (United National Convention on Rights for People with Disabilities). These rights extend specifically to include the needs of people with disabilities to have choices equal to others so that individuals have the option to choose where they live and with whom they live as well as having access to the supports needed to achieve inclusion in the community (United Nations 2006). Ireland ratified the UNCRPD in March 2018.

1.4.2 Homelessness and housing policy in a European context

Homelessness in a European context is defined by the European Typology of Homelessness and Housing Exclusion (ETHOS) developed by FEANSTA (2011). This definition takes account of homelessness as being not just without a roof (i.e. sleeping rough), but also house-lessness (those living in temporary accommodation), insecure housing (staying with friends/family or under threat of eviction) and housing that is inadequate in that it fails to meet the needs of the people living there or is associated with inconveniences (EU 2014). It is this definition of homelessness which guides the current study.

While difficult to assess exactly the number of people in the European Union experiencing homelessness under the FEANSTA classification, the European Commission estimates that around 4.1m people experience rooflessness or homelessness annually (EU 2014).

1.4.3 Homelessness and discrimination in the EU

There has been concern within the UN that people with disabilities (especially those with intellectual disability and/or psychosocial disabilities) continue to live in institutions across the European Union and that European Structural Funds are being used in individual member states to retain residential institutions rather than developing supports for people to enable them to live in local communities (United Nations 2015).

An estimated 1.2m people with disabilities live in institutions around Europe, and institutional placement is increasing. Conversely there is a lack of community-based services which would enable people with a disability to integrate into the local community or gain the supports needed to live independently (United Nations 2017).

In Europe, people with intellectual disabilities experience discrimination which prevents them from having the same rights as others. Furthermore, this discrimination filters through to the family caring for an individual with ID and/or ASD. In many instances, they live in poverty because of being unable to find employment due to the need to care for their relative (Inclusion Europe 2019).

1.5 Homelessness as a social determinant of health

The Social Determinants of Health Framework (Dahlgreen and Whitehead 1991) identifies housing as an important non-medical or social determinant of health. In essence, an individual's health and future health outcomes are directly impacted by the conditions of daily life and resources available to them; and inequities in these social determinants (greater poverty, poor quality housing, unsafe neighbourhood to name a few) result in inequities in health (World Health Organisation 2012). Reducing and improving the experiences around the social determinants of health is an essential means to achieving equity in health and is defined as 'the absence of systematic disparities in health (or in the major social determinants of health) between groups with different levels of underlying social advantage or disadvantage' (Braveman & Grushkin 2003). Thus, beyond the rights-based framework that testifies housing as a human right, access to quality, stable housing directly impacts on health outcomes and subsequently increases pressure on the health system.

1.6 Homelessness and housing policy in an Irish context

Legislation in Ireland around homelessness is based on four key Governmental Acts [Health Act 1953; Childcare Act 1991; Housing Act 1988 Housing (Miscellaneous Provisions Act 2009)]. The 1988 Act provided the first legal definition of homelessness in Ireland, which is less inclusive than the FEANSTA classification. Section 2 of this Housing Act defines a person as homeless under three specific circumstances: lack of reasonable accommodation; living in a shelter; or where the person cannot provide accommodation from their own resources. The Health and Childcare Acts provide a legal definition which translates into different types of homelessness: the visibly homeless (rough sleepers or those in emergency accommodation); people likely to become homeless though economic difficulties, or through the threat of violence (Dublin Regional Homeless Executive 2019). This narrow definition is at odds with the more inclusive ETHOS (FEANSTA 2011) interpretation of homelessness excluding as it does situations where individuals are in insecure, inappropriate or inadequate housing (Dublin Regional Homeless Executive 2019). There is also variation in definitions between homeless charities and AHBs in the practical provision of services, which has implications for those seeking housing (Downey 2008).

Currently in Ireland, housing is not a basic human right enshrined in the Irish Constitution for anyone in the population. Furthermore, research indicates that there is a noted absence of core human rights in both health and housing for people with intellectual disability (O'Donovan et al 2018).

Estimating the numbers of people experiencing homelessness in Ireland is made difficult by the legal definition used, as many who would be included under the European ETHOS definition are excluded by nature of the Irish definition (Dublin Regional Homeless Executive 2019). The most recent homeless figures from the Department responsible for housing puts the number of adults who are homeless at 9,335 in January 2020 (DHPLG 2020). However charitable and NGO (Non-Governmental Organisation) services who work in supporting homeless people and families suggest a larger figure, with one family-focussed agency listing the number of people (including children) at 10,271 people for the same period. Part of this difference may be down to the fact that the Department of Housing Planning and Local Government changed how data on homelessness was recorded last that year, deciding to exclude those in 'own door' (self-contained) accommodation from the statistics (Focus Ireland 2020).

1.7 Homelessness and housing policy in disability in an Irish context

Historically, from the 1860s onwards in Ireland, special residential centres were developed, mostly by religious orders, to provide accommodation for children or adults with intellectual disabilities. These orders tended to congregate individuals by gender, with male religious bodies caring for males only, while nuns cared for females. This started to change in the 1950s with the advocacy of families and friends of people with intellectual disabilities, and Ireland began to see the development of community-based services. Irish Government policy and strategy, from the 1980s onwards, has focussed on community inclusion for people with an emphasis on equality, citizenship and rights (Department of Health 1990; 1996; 2004).

People with intellectual disabilities in Ireland have traditionally lived either at home (cared for by relatives) or in institutional settings (with care from disability Service Providers) (Health Research Board 2018). In Ireland, for example, seven out of ten people with an intellectual disability live at home with family (Hourigan et al 2018). Over a ten-year period from 2007 to 2017, the number of both children and adults being cared for at home by a family member had increased by 15.4% and 24.5% respectively – three times the population growth for the general population according to the Irish census (Central Statistics Office 2016).

Of those living at home, and engaged in disability services of some kind, over 10,000 are adults and more than four thousand are over the age of 35 years (Health Research Board 2018). However, there is concern that a combination of ageing parents and little evidence of forward planning (for care to be replaced by more formal services) will lead to a future crisis with this group. Recent research has pointed out that the traditional sociodemographic norms that were associated with family caregiving are in decline, and that this may lead to the placement of older family members needing out of home care (Brennan et al. 2017). Currently there are 656 individuals with ID and/or ASD living with parents who are over the age of 70 years (Inclusion Ireland 2019).

There is a need for planning of appropriate housing options for people with ID and/or ASD as they and their carers age, as reflected in demographic change. The number of people with ID and/or ASD over the age of fifty years living with family has risen from 5,200 in 2012 to 5,700 in 2015, and this increase would suggest that an additional 400 to 500 places would be needed to meet this need by 2020, rising to between 700 and 800 places by 2025. In addition, 15% of people with ID and/or ASD live with family, a situation which is not sustainable requiring a further 200 placements by 2020 and 370 by 2025 (NDA 2018a).

For those in institutional settings, Irish policy has been led by the UN Convention on the Rights of People with Disabilities (UNCPRD) (United Nations 2006). This Convention, signed by Ireland in 2007 but not ratified until 2018, has led to the establishment of Irish legislation around rights to be implemented into law so that Ireland could meet its obligations to people with intellectual disability and their families under the Convention. Those obligations focussed on the need to move people out of congregated settings. A congregated setting is defined as one where ten or more people with disabilities are living (Health Service Executive 2011).

This ‘de-congregation movement’ reflects a societal move towards a rights-based approach for individuals with ID and/or ASD. Over the past decades there has been a considerable shift in housing standards to support such individuals with ID and/or ASD to move from congregated settings to live independently. This policy is most notably outlined in the ‘A Time to Move on from Congregated Settings’ report published by the HSE in 2011. The proposed new model of accommodation envisaged both accommodation and support in the community in the form of either dispersed housing (apartments/houses similar to that of the general population scattered throughout localities) with individualised supports (supported living) (Health Service Executive 2011). However, the Intellectual Disability Supplement to the Longitudinal Study on Ageing (IDS-TILDA) has highlighted that older people with intellectual disability in Ireland are changing residence, but not always to community settings and may have limited or no involvement in these transitions (O’Donovan, 2016).

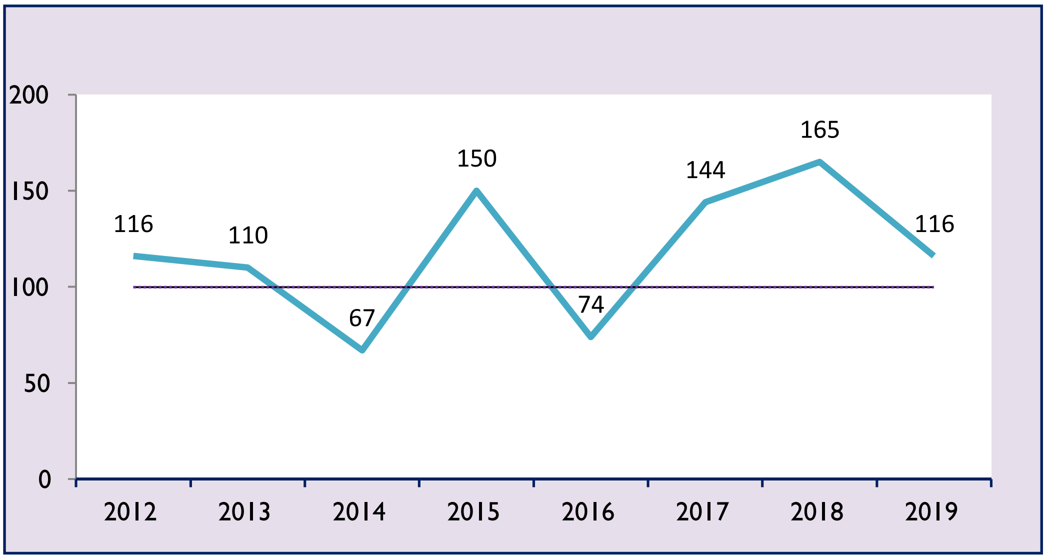
Specifically, the National Disability Inclusion Strategy (Department of Justice and Equality 2017) is working towards greater inclusion with national policies and strategies around employment, independence and mental health which aim to help meet those obligations (NDA 2018a). Amongst these is the recent introduction of a ‘Health Passport’ which people with ID and/or ASD can use to explain their needs when interacting with local health services (Health Service Executive 2019).

However, it is equally clear that there is no funding to match the ambition of this strategy for inclusion. Gross spending on disability services fell by 7% in the years 2009 to 2016 while the NIDD recorded an increase of 8.5% in persons with ID and/or ASD requiring support services in the same time frame (NDA 2018a). A recent report on disability funding generally (as reported in the Irish Times) found that while the HSE is at present spending about €2 billion for disability services, there was a funding gap of €78.5m in 2019 alone (Irish Times 2020).

The Irish Government has published a national housing strategy for people with a disability as part of meeting the obligations of the UNCRPD – the National Housing Strategy for People with a Disability (NHSPWD) (Department of Health 2016). Its vision is to facilitate access for people with disabilities to a range of housing and related services and to support them to live within that housing option. Furthermore, this would be facilitated by delivering these options in a sustainable way and one which would allow people with disabilities to experience equity of opportunity, choice and independent living (Department of Health 2016). However, this policy has not been resourced to meet the current and emerging needs of children and adults with ID. Nor does it reflect the barriers to and needs of individuals with ID and/or ASD and their families. In the period 2009 (when over four thousand individuals lived in congregated settings) to 2017 nearly 1,600 people have moved into community or supported living accommodation (Irish Council for Social Housing 2018) and this is supported by the latest Government housing strategy – Rebuilding Ireland (DHPLG 2016).

The diagram below displays the number and trend line of transitions completed from 2012 to 2019. Annual variations are evident but from over the last two years the number of transitions had increased in line with expectations and the provision of housing through the capital funding stream (Health Service Executive 2020).

Diagram 1.1 Number of Transitions and Trend Line 2012 - 2019



Source: Time to Move on Policy: Annual Progress Report 2020

However, not all transitions are to envisaged community settings. The following table indicates the number of people and the changes in the population in congregated settings from 2012 to 2019 (Health Service Executive 2020).

Table 1.1 Movements in the Congregated Settings Population from 2012-2019

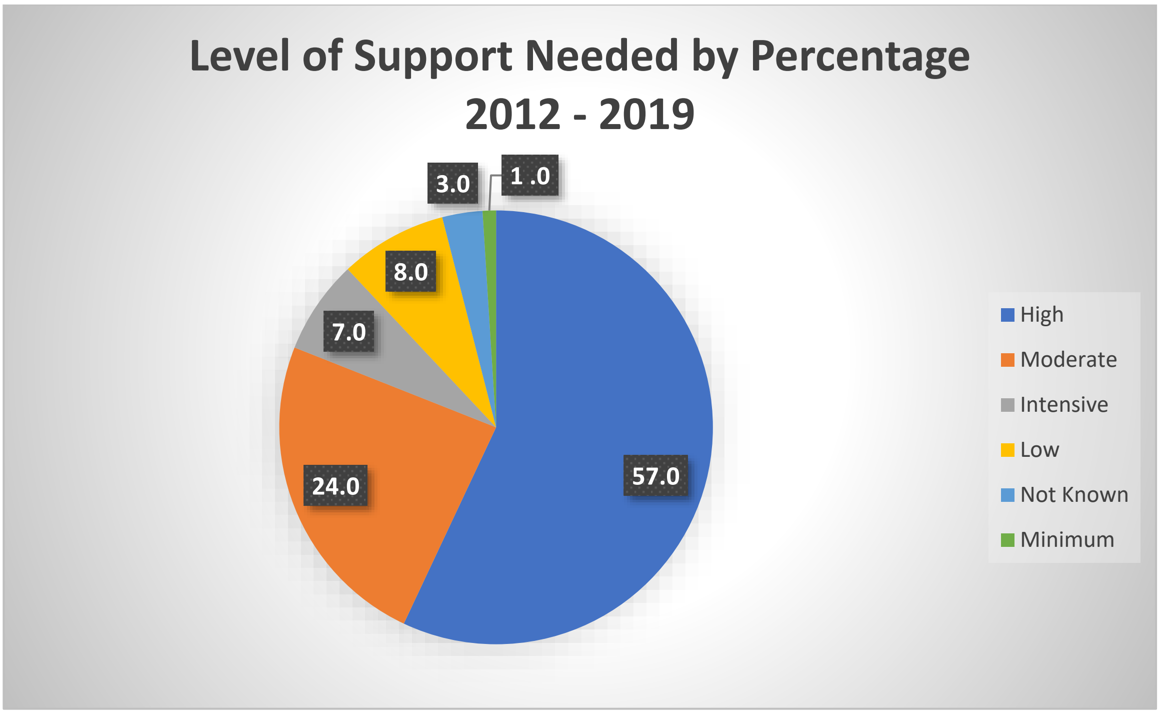
Number of people who transitioned	942
Number of people who passed away	789

Number of people admitted or re-admitted	278
Number of residents at end of 2018	**1,953**

Source: Time to Move on Policy: Annual Progress Report 2020

Where individuals are moved to community-based housing, additional supports are essential to successfully guide them through their transition and establish ties to their new community. The level of these supports varies widely, as Table 1.2 below indicates, but with the majority (64.0%) deemed to need either high or intensive levels of support.

Diagram 1.2 Level of Support Needed for People who Moved 2012 - 2019



Source: Time to Move on Policy: Annual Progress Report 2020

A systematic review of the literature (Lombard et al 2019) identified that while moves to the community can increase the quality of life for individuals, discharge from congregated settings can be a risk factor for homelessness due to insufficient or inappropriate supports (Backer, Howard and Moran 2007; Burns 2003).

1.8 Housing and housing supports in Ireland

1.8.1 The need for social housing support

There are a number of reasons a family or individuals (whether or not they have an ID and/or ASD) need social housing support, and Table 1.2 (below) illustrates that the reasons vary from economic necessity to disability (Housing Agency 2020). Between the years 2013 and 2019 there was an increased social housing need generally, and the number of people listed as homeless in the general population grew from 2,499 in 2013 (2.7%) to 9,335 in 2019 (9.0%) – a 233.3% increase (Housing Agency 2020).

The percentage of those seeking financial support for housing and having an Intellectual Disability is 2.2% in 2019 (n=1,550 persons). This figure could be under-representative of the true figure, reflecting issues around the lack of diagnosis of borderline/mild ID and/or ASD – those who are not known to services and have not received a diagnosis (McKenzie et al 2019). A UK study outlined the challenges of identification and measurement in the homeless population and found that 12% of 106 rough sleepers had undiagnosed ID and/or ASD (Churchard et al 2018).

The number of people with ID and/or ASD seeking financial support for housing has been increasing year on year since 2013 (at 1.1%, n =1,078). This may be due to factors, including greater advocacy around access to social housing as well as more housing becoming available in addition to the effects of de-congregation.

Table 1.2 Main Need for Social Housing Support

Main Need for Social Housing Support	% in 2013	% in 2019
Dependent on Rent Supplement	51.8	28.5
Unsuitable accommodation	22.6	28.2
Requirement for separate accommodation	10.6	17.5
Homeless, institution, emergency accommodation or hostel	3.1	9.1
Overcrowded	3.2	5.3
Physical disability	1.5	0.7
Mental health disability	1.1	2.3
Intellectual disability	1.1	2.2
Medical/compassionate grounds	3.2	1.2
Unsustainable mortgage	0.7	1.4
Unfit accommodation	0.7	0.7
Sensory disability	0.2	0.5
Other form of disability	0.2	0.0
Total Number of Households	**89,872**	**68,693**

Source: Housing Agency 2020

This lack of social housing means that people are forced into the private rental market. People with disabilities report facing discrimination when trying to rent (Watson et al 2018). Properties which are accessible, affordable and with a landlord who will accept HAP (Housing Assistance Payment) are limited and this cohort is more than twice as likely to report discrimination and are ‘among the more disadvantaged groups in Ireland when it comes to housing’ (Watson et al 2018). There are also issues around accessibility of rental properties in Ireland, with an earlier report stating that people with disabilities were found to be, like students, ‘a difficult tenant group’ according to Irish landlords. The report suggested the provision of financial incentives to encourage landlords to adapt properties to enable independent living for people with disabilities (Housing Agency 2010).

1.8.2 Homelessness prevalence and ID and/or ASD in Ireland

Prevalence rates for individuals with ID and/or ASD that are living homeless in Ireland have yet to be identified, with a dearth of research exploring the relationship between the two although a research study is currently underway which focuses on ASD within the homeless population (Dublin City University 2019). Statistics are not available for those with ASD within the general population, though the estimate is 1.5% of the population (Boilson et al 2018). Despite this, the experiences and perspectives of front-line staff working in both the disability sector and the homeless sector attest to the fact that people with ID and/or ASD are experiencing homelessness (Disability Federation of Ireland 2018).

1.8.3 Homelessness and families in Ireland in the general population

Homelessness in Ireland in the general population has grown year-on-year and the most recent figures suggest that more than ten thousand people were homeless in November 2019 (Focus Ireland 2020). It is now estimated that one in three people in emergency accommodation is a child. This excludes those in squats, couch surfing, in refuges or rough sleepers. The number of families who have become homeless has increased by more than 300% since 2014. Furthermore, of the 68,693 households qualifying for social housing in 2019, more than a quarter had been on a housing list for more than seven years (Focus Ireland 2020). The main drivers for homelessness in the general population are structural and personal factors (Focus Ireland 2020).

In the absence of social housing many presenting as homeless are provided with temporary solutions/emergency accommodation. It is widely recognised that any length of time spent in temporary accommodation (Hotel, Bed and Breakfast or Family Hub) has a detrimental effect on family life in the general population, especially where children are involved (DHPLG 2016).

A US study found that families, in particular, were negatively impacted by living in such emergency accommodation and suggested that additional financial aid be provided to prevent homelessness in the first place. In cases where this cannot be avoided, that grants for housing stabilisation and relocation be provided to allow families to return to ‘normal’ living situations quickly (Culhane and Metreaux 2008).

More recent Irish research indicates that individuals, and families, placed in ‘hubs’ or other unsuitable accommodation have little control over their environment and fear making complaints as they felt it would render them homeless once more (ICON 2019).

There are also significantly more families who are new to Ireland in homelessness services – at 33% of the population as opposed to 11.6% in the general population in Ireland. [In this instance, ‘new to Ireland’ refers to people who have migrated to Ireland and have been issued with an Irish Residence Permit and as such have permission to stay in Ireland (Department of Justice and Equality 2020)]. While the reasons for both cohorts to enter into homelessness are similar (forced out of their rental property), families who are new to Ireland, having smaller social networks, and are less likely to have family and friends to help. They may also be less aware of the supports available to them, leading to an acknowledged lack of equitable support (Dublin Regional Homeless Executive 2018).

1.8.4 Family support for people with intellectual disabilities

While alternatives to living at home and being cared for by families are available in some countries, most children and adults with an intellectual disability have been, and continue to be, cared for by family (Braddock et al. 2001). Families have lobbied extensively for community services to allow this care to continue, nevertheless additional demands have been placed on families (and mothers in particular) to provide this care (Patton et al. 2018; Wang 2012).

While there is a growing body of research looking at the resilience of families caring for people with disabilities (Grant, Ramcharan and Flynn 2007), studies over a number of years indicate that parents caring for children with an intellectual disability experience high levels of parent-related stress which permeate into a number of aspects in their lives, including mental health (depression and anxiety) and are statistically significantly more likely to experience poverty and social exclusion than the general population (Burton-Smith et al 2009; Emerson and Brigham 2015; Hubert 2011; Johnson et al 2018). In spite of this, the spend on respite services (traditionally a number of overnight stays per month at the location of a Service Provider) accounts for only 2% of the HSE Disability Service budget – the lowest percentage of any spend in the budget. It has been noted that the provision of respite care may be one of the critical factors in supporting families to cope, thereby reducing the demand for residential care (which accounts for 63% of the budget) (NDA 2018a).

And while structural factors are more likely to be the cause of recurring family homelessness in the general population than individual factors, especially income levels, there is an issue with recurring homelessness. Research finds that it is insufficient to purely provide payment benefits, but to give families the opportunity for earned income to allow for quality of life following housing (Kim and Garcia 2019). Housing interventions do not always mean that homeless families who are residentially stable can become economically self-sufficient to support their needs (Bassuk et al 2014).

These risks place families into a cohort which is more likely to experience recurring homelessness than others, meeting as they do many of the markers for a pathway into homelessness on both a structural and personal level.

The Danish social housing model aims to overcome this by 'levelling the playing field' in terms of providing people with disabilities with a range of services and interventions, free of charge, and regardless of income levels. They include practical help, housing adaptations as well as special furnishings, even to the purchase of household items (such as washing machines), which would make their everyday tasks easier (Housing Agency 2010).

1.9 Structural factors leading to homelessness in people with a disability and their families

1.9.1 Poverty and deprivation

Poverty can be associated with intellectual disability (via exposure to a wide range of environmental and psychosocial dangers) (Emerson et al 2010) and families supporting a child or an adult with intellectual disability are at an increased risk of falling into the poverty trap as a result of the financial and social impact of caring for their family member. Even where there are two parents, usually only one parent can work due to the high care needs of their child (day to day caring as well as attending appointments etc). In one parent families, they also cannot work and tend to rely on social welfare payments. This association accounts partly for the health and social inequities experienced by people with ID and/or ASD and their families, leading to a number of social problems, the most notable of which is homelessness (Chapman et al 2008; Emerson 2007; Emerson et al 2010).

Global cognitive impairments are more prevalent in the homeless population than in the general population, and below-average IQ is considered a risk factor for homelessness and vulnerability (Brenner et al. 2017; Mercier and Picard 2011). Entrenched homelessness leads to the deterioration of untreated conditions (such as addiction and or mental health issues) in this population, underlining the need for early intervention (Mercier and Picard 2011).

In Ireland, a reported 1.4% (n=66,611) of the population experienced an intellectual disability in the 2016 Census – more than 15% (n=8,902) higher than the 2011 Census (Central Statistics Office 2016). The gender breakdown for ID and/or ASD (engaged in services) is 59.1% (n=16,768) male and 40.9% (n=11,620) female (Health Research Board 2019).

People with disabilities in Ireland are three times as likely to experience poverty with less than one-fifth (17%) of people with an intellectual disability in employment and more than half (56.5%) having experienced difficulty or an inability to work or go to school or college (Central Statistics Office 2016). Rent in Ireland, (Dublin specifically) is high and in most instances beyond the means of people who depend on state benefit as their sole income (Simon Community 2019).

Carers Allowance, at time of writing, is €219 per week for those aged 66 and under caring for one person. Disability Allowance is paid at €203 per week, while those on Jobseeker’s Assistance receive the same payment of €203 (Citizens Information 2020). Coupled with the fact that this cohort may need home adaptations, specialist disability aids, higher levels of home heat and light as well as a greater spend for transport (due to lack of appropriate public transport) suggest that their level of income needs to be higher to meet those needs. At the present time, such adaptations are means tested (Watson et al. 2018). By comparison, the Danish social housing model provides a range of supports which are not means tested (Housing Agency 2010).

However, while there is a considerable body of research linking Intellectual Disability and poverty, there is very little understanding of how this impacts on the life experiences of people with ID (Emerson and Parish 2010).

Certainly, for children there is emerging evidence that environmental factors can lead to increased 'conduct difficulties' in children with ASD and ID [See Appendix 1]. The risk environmental factors referred to in the research include living in situations where there is low income, material hardship (lack of basic home amenities), unemployment, poorly maintained housing (damp etc) and an inadequate neighbourhood. Across any one level of such risk, children with ASD displayed persistent conduct difficulties, while for children with an ID, conduct difficulties increased with medium and high exposure to environmental risk (Emerson et al 2014).

1.9.2 Education and communication

Cognitive and functional impairments have been suggested as a challenge that can lead to communication difficulties, socioeconomic disadvantage and social discrimination for individuals with ID (Burge 2009). Difficulties navigating social norms can compound these stressors (Lougheed and Farrell 2013).

People with an intellectual disability are amongst a group with the poorest literacy skills, having been historically excluded from mainstream education (Van den Bos et al. 2007) with most not progressing past primary school and the inability to read poses 'significant additional limitations' (Koritsas and Iacono 2007). More recent efforts to include people with ID and/or ASD into mainstream schools while successful, has not translated into subsequent employment. A longitudinal study tracking Irish children of school going age on the NIDD database over a ten year period from 2004 to 2014 found that of those still engaged in services, most were still connected to traditional day or training centres following completion of post primary education, with only a few in employment related activities (McConkey, Kelly, Craig and Keogh 2017).

Social control strategies, such as the use of 'force', 'coercion', or 'bargaining', when exerted over vulnerable individuals that struggle with social situations can lead to further challenges such as resistance, confusion and avoidance of supports (Johnsen, Fitzpatrick and Watts 2018). This in turn negatively impacts accommodation status as support services can conflate eligibility for accommodation as conditional, dependent on engagement with services (Evans 2011; Markee 2009).

1.9.3 Economic dependence

Lack of economic independence is a notable factor leading towards homelessness for individuals with intellectual disabilities and their families. Unemployment is often a factor contributing to their homelessness (Nishio 2017; Shamblin et al 2012), while simultaneously employment is a primary challenge for individuals with intellectual disability resulting in high levels of dependence on social welfare payments and challenges faced both gaining and retaining employment (Watson et al 2017). The financial skills and high-level economic concepts related to day-to-day living (budgeting and costs) can also be a significant challenge and they are reported to present clinically at higher risk of financial and emotional abuse and neglect in comparison to other homeless individuals (Lougheed and Farrell 2013).

People with a disability emerge as one of the most disadvantaged groups and are over-represented amongst the homeless population (Durbin et al 2018a). Experiencing high risks of discrimination and housing and environmental deprivation, more than one-in-four homeless people in Ireland have a disability (Grotti, Russell, Fahey and Maitre 2018).

There is a dearth of information on the level, presentation or risk of homelessness experienced by people with ID and/or ASD in Ireland. Irish policy asserts the rights of people with disabilities to independent living of their choosing. However, implementation of policy has not been fully realised and access to appropriate and secure housing continues to be a challenge for both adults and family who have children with ID and/or ASD (Inclusion Ireland 2019).

1.10 Personal factors leading to homelessness

1.10.1 Invisibility

There is an acknowledged 'invisibility' of intellectual disability, which is often misclassified and many who are not engaged in services are either homeless or in unstable living conditions across the life course (Leedham 2002; Simons 2000; Talbot and Riley 2007). This cohort is more likely to experience psychological distress and to be substance dependent, and thus in need of specific targeted supports (Van Straaten et al. 2014).

The situation for people with Autism/ASD is similar, with a high level of non-diagnosis and therefore limited support. In the UK, the full-time employment rate for adults with Autism is low at 16%, and more than two-thirds (70%) of adults there feel they are not getting enough support (National Autistic Society 2017). Many do not have a clinical diagnosis, and a disproportionate amount of people with ASD experience homelessness (Campbell 2015; Pritchard 2010) and unsuitable accommodation (Kargas et al 2019).

In the UK there is widespread adoption of a social model of disability and the private rental market operates an Accessible Property Register (Housing Agency 2010). However, it is argued that it has not permeated into the field of ASD leading to a 'systematic oppression of autistic individuals' reflected in the social and economic difficulties they experience (Stafford and Wood 2017).

As a result of a growing awareness that there is a disproportionate amount of homeless people who have ASD in the UK, some work has been done on improving communication (by providing visual information) and structuring service delivery as well as specific guidelines for landlords renting to people with ASD (Glasgow City Council 2010; Pagler 2011). Similar work has been done in Ireland with the publication of a guide and eLearning tool by the National Disability Authority which is aimed at local authority housing officers in helping them to become familiar with the needs of a person with ID and/or ASD (NDA 2018b). However, this may be insufficient and one of the main reasons for this is the fact that there is often a lack of a diagnosis of Autism throughout an individual's life-course. This in turn contributes to people with ASD being perceived as 'different' and an accompanying inability for society to be able to accommodate that difference (Pagler 2011; Stone, Dowling and Cameron 2019).

People with disabilities are over-represented in the prison population, particularly those with an intellectual or psychosocial disability (IPRT 2020, Richies et al, 2006). Studies in the UK suggest that between seven and twenty-three per cent of prisoners in Wales and England have an intellectual disability (Ali et al. 2016). Housing was of most concern to prisoners with a disability, many of whom had already experienced homelessness (IPRT 2020).

1.11 Social issues around homelessness

While the pathways into homelessness follow patterns in a non-disabled population in terms of structural and personal causes, there are factors around social issues which compound difficulties for people with disabilities, mostly around social connectedness and acceptance.

Social capital, defined as an enduring network of support by virtue of group membership (Bourdieu 1985) focusses on concepts associated with positive consequences in terms of health and resilience (Widmer, Kellerhals and Levy 2004; Widmer, Chevalier and Dumas 2006). The notion of family relationships as a form of social capital focusses on 'high-density' relationships where individuals are interconnected and can have a number of people within their network to support them, even if not all do so (Coleman 1988; Baker 1984).

Within that definition of social capital, families with blood-ties and/or partnership ties provide densely connected family support networks while those based on a friendship basis provide a type of 'bridging social capital' (Widmer 2006).

Research indicates that individuals with an intellectual disability have lower levels of family based social capital than the general population (Widmer 2006).

Amongst populations of homeless individuals with intellectual disabilities, a breakdown in their social support network has been identified as a contributing factor to unstable housing arrangements – especially the death of their significant carer (Mercier and Picard 2011; Nishio, Horito et al. 2017). Care provision then, for homeless people with disabilities, is needed throughout the transition out of, and following exiting, homelessness (Van Straaten et al. 2014).

There is also a difference in social capital depending on whether a person is residing in a formal care structure or in the family home. For those in care structures, research would appear to indicate that the social networks of people with an intellectual disability are somewhat limited (Robertson et al. 2007) and only a small number of individuals living in care structures had regular family contact (Stoneman and Crapps 1990).

Analysis from IDS-TILDA in Ireland found that individuals living independently or with family were more likely to have non-resident friends. Conversely, those in congregated or even community-based residences had less friendships. Individuals living close to family, even in institutionalised settings, had greater levels of contact with family than those living at a distance. However, the study also found that older people with an ID and/or ASD fare far worse than the general population in terms of friendships and social capital (McCausland et al. 2017).

Individuals with an ID and/or ASD living with family showed a marked contrast in terms of their social networks (Krauss and Erickson 1988; Krauss Seltzer and Goodman 1992).

The conceptualisation of family relationships as social capital suggest that individuals belonging to such a group benefit from their membership of it – such as improved physical and psychological health and an overall increased resilience against stressful life events (Widmer, Widmer, Chevalier and Dumas 2005).

However, ID and/or ASD can create a barrier to family functioning and can mean excessive work (in the level of care that has to be provided to an individual) and negatively affect the family dynamic (Heru and Ryan 2004; Jokinen and Brown 2005; Widmer et al. 2010). There is also evidence to suggest that this level of care, coupled with the often challenging anti-social behaviours of some people with ASD, can compound a family's difficulties, especially in relation to housing where issues arise with landlords and co-tenants or neighbours (Glasgow City Council 2010; Pagler 2011; Stone, Dowling and Cameron 2019).

Having an intellectual disability remains a powerful social identity with the 'fear of difference' acting as a barrier to full engagement with the wider community and a barrier to equity of human rights (Anderson and Bigby 2016; Beart, Hardy and Buchan 2005; Scior and Werner 2016). Stigma, as a social construct, refers to the attitude, prejudice and discrimination of a dominant group towards a minority group, leading to misconceptions about their attributes and capabilities and are perpetuated by the bias of social structure (Corrigan 2004; Corrigan Roe and Tsang 2011).

Stigma, as a mark of 'social disgrace' allows others to discredit individuals based on specific attributes that are seen to set them apart. Moreover, this social stigma extends to those who are associated with the target grouping (Goffman 1963). This, as a form of 'public stigma' can lead to self-stigma, where the target individual becomes aware of and takes on this public stigma. Self-stigma can be experienced not only by the individual but also by the people affiliated with the stigmatised person, especially families often leading to social withdrawal and subsequent health problems (Ali, Hassiotis, Strydom and King 2012; Mitter, Ali, Scior 2019).

As discussed earlier (see Section 1.11a) children with ID and/or ASD living in inappropriate and/or poor environments display distress in the form of conduct difficulty. Defined as a group of persistent and behavioural problems in young people, they are subsequently viewed by adults, other children and social agencies as 'bad' or delinquent (American Academy of Adolescent and Child Psychiatry 2020) and exposed to stigma and social exclusion.

A valuable tool in countering this stigma has been the emergence of Social Role Valorisation (SRV). It is a concept aimed at creating or supporting socially valued roles for people who are already societally devalued. Devalued individuals, as a result of their negatively valued differentness, face being rejected by community, society and even family and can be cast into negative social roles. The major goal of SRV in creating valued social roles is to overcome this prejudice by ensuring that society sees them as valued individuals, therefore negating social stigmatisation (Osburn 2006).

The living conditions of people with an intellectual disability often differ from those of the general population, particularly in relation to poverty, employment and social life (Umb-Carlsson and Sonnalden 2006; Emerson and Parish 2010).

There is little doubt that higher levels of social competency enables greater social inclusion (McConkey 2005) and that this can be greatly enhanced by support staff helping individuals to acquire the skills which require them to act in a supportive/teaching role rather than purely a caring role (active support) (Mansell et al 2002). Whilst many of the barriers were physical ones (such as transport) an identified need was that of an attitudinal shift from the community which would result in a greater level of integration, where a concerted and sustained effort was made to involve people in local social, religious, educational and work settings (McConkey 2007).

1.12 Navigating social housing in Ireland

Housing in Ireland comes under the remit of, primarily, the Department of Housing, Planning and Local Government (DHPLG) as well as other Statutory Agencies. Criteria for qualification is not universal and varies widely.

Accessing social housing in Ireland is 'fraught with difficulties' and a combination of long waiting times as well as a complex system of bureaucracy leaves people (even those without a disability) in need of considerable help and guidance in navigating the housing system. Furthermore, if a first offer of housing is refused, and the Local Authority does not agree with the reason for refusal, the applicant's priority may be reduced. Priority is given to those longest on the waiting list as well as those with identified medical need. In addition, there are specific housing categories – the over 55s, the homeless and traveller specific housing (Housing Agency 2020). If the applicant refuses more than one 'reasonable offer' within a year, they are suspended from the housing list for a year during which time they cannot access rent supplement (Citizens Information 2020). The waiting list can be as long as seven years. (Focus Ireland 2019). [See Appendix 3 for more detail on the process of entering the waiting list].

Homeless households are often denied any involvement in deciding the type of accommodation that they are given, placing them at risk of repeated cycles of homelessness because of inadequate housing or location unsuitability e.g. (poor access to services, absence of support structures such as families and friends) (Kiddey 2014).

In 2016, 15% of people with disabilities were renting social housing through a Local Authority or a housing body compared to 9% of all households in the general population (Central Statistics Office 2016).

Care at home is the preferred site for the care of individuals with complex needs, recommended in health policy and advocated for by professionals (Brombley 2008) and many schemes and grants are available in Ireland for house adaptations to facilitate this (DHPLG 2019). However, many of these grants are available in the context of people with physical disabilities and those who are ageing. The financial supports are means tested and many families find they do not fit the criteria due to income levels, unlike the Danish model which is not means tested (Housing Agency 2010). Moreover, meeting the needs of children with disabilities has been developed independently over time by a series of statutory, voluntary and NGO organisations and are focussed on the provision of health and education, leading to patchy provision around the country (SNPA 2020). For over 10 years, the HSE has tried to consolidate the work of these groups through a specific programme (Progressing Disability Services for Children and Young People) aimed at progressing services for children and young people with special needs (Health Service Executive 2009). However, even within this, there is currently no Government policy covering housing for children (young and adult children) with a disability or their families.

1.13 Pathways out of homelessness

International research suggests that here is no one single solution to assisting individuals or families who have themselves or a child with ID and/or ASD in regard to homelessness. Rather, there is a need for both preventive and individualised support which follows the individual and/or their family throughout their life course.

No specific literature on preventing families of children with intellectual disability from entering homelessness or indeed interventions to support exiting homelessness have been identified.

Some research has been published regarding adults with intellectual disability in the homeless population. To date the focus has primarily been on the acknowledgement of the over representation of people with intellectual disability in this population, with little by way of best practice strategies to support adults with intellectual disability out of homelessness. Though it is an emerging area and some notable work in Canada, the Netherlands and the UK deserve mentioning.

1.13.1 Preventive support

Some innovative approaches to support families and adult children with ID, as well as adults with intellectual disability independent of families, have been identified in Australia.

In Australia (where 17% of the population lives with a disability or long-term health condition) there is evidence of poorer housing outcomes for this group. An initiative targeting this issue used the construction of an Index of Relative Homelessness Risk (IRHR) that enabled comparison of relative exposure to homelessness based on type of disability. It found that those with education or employment restrictions, psychological and intellectual disabilities and mental health issues were particularly vulnerable to extreme levels of homelessness risk and in need of specific targeted support. Noting that co-morbidity had not been captured, the study acknowledged that this would increase vulnerability to homelessness risk (Beer et al 2019).

These are not specific strategies for preventing the pathways into or supporting pathways out of homelessness. Instead, the focus is on providing sustainable, supported, community-based living arrangements that enhance independence, autonomy and community integration for people with intellectual disability. These approaches are aligned with direct payments and circles of support. Such independent supported living models are worth future examination in this context (Cocks et al. 2017; Fisher et al, 2008). These approaches could transfer well to the Irish context in that they could support non-congregated yet appropriately supported living options for people with intellectual disability.

1.13.2 Individualised support

A US programme designed to identify and support people with disabilities used a cross-agency approach by combining a number of individual support agencies into one single ‘task force’. This allowed for identification (through outreach and diagnosis) of people with disabilities who were experiencing difficulties accessing benefits and, in many instances, housing. This cross-agency approach enabled applications to be processed correctly and quickly, with two positive outcomes. The first was a greater level of financial and health support for people with disabilities and secondly that the project reduced the administrative burden on (social protection payment equivalent) staff (Kennedy and King 2014).

1.13.3 Cross-sector collaboration

A recent Canadian study describes the development of a specific cross-sector partnership that was developed to support the efforts by adults with ID to exit homelessness. Focussing on shelter residents with ID and/or ASD, a specialised primary care team was established to link health care, housing and ID services in the city of Toronto. Using this integrated service approach, (which was grounded in the principles of Housing First) the team acted directly with input and collaboration from target individuals. This enabled success in addressing complex support needs paying particular attention to choice and compromise. All stakeholder groups were involved, leading to greater communication and collaboration and subsequently engagement with the process leading to positive outcomes (Lamanna 2020).

The Danish social housing model, having decentralised housing to the remit of their local authorities, uses whole sector responsibility. In this way, disability policy is not just under the aegis of health and social policy, but also transport, education, employment and housing (Housing Agency 2010).

1.13.4 Continued support

For both families and individuals, accommodation alone is not sufficient for a successful transition from homelessness. The care needs of individuals with ID and/or ASD who experience homelessness need to continue following housing. They include, but are not limited to, the ability to cope with challenges of caring and making adjustments as well as meeting basic needs and maintaining stability. Otherwise they face cycling in and out of homelessness for prolonged periods of time (Burra, Stergiopoulos and Rourke 2011; Iaquinta 2016; Van Straaten et al. 2014).

The need for further research in this area has been highlighted (Durbin et al, 2018a, Durbin et al, 2018b). In particular, the need to fully explore the Housing First policy for people with intellectual disability, the appropriateness of such models for people with severe/ profound intellectual disability and complex needs, and the expectation that these needs are more enduring and complex compared to other sub-groups of the population and as such would require enduring supports (McKenzie et al, 2019; Durbin et al, 2018a).

Individual street homeless tenants with significantly higher cognitive difficulties drew on more resources than individuals accessing long term shelters. These resources included advocacy, escorting, physical and mental health treatment along with additional assistance in fiscal matters as well as housing. The enduring care needs of an individual transitioning from homelessness is more about their capacity to cope on a day-to-day basis than the context in which they find themselves when housed and they are in need of additional supports and adjustments (Levitt et al. 2012). This is of particular concern to individuals with ASD traits who may be undiagnosed, presenting a key challenge in identifying this group whose clinical assessment is affected by other factors (substance misuse, homeless environment, mental health) (Fazel et al 2014).

For families, especially those with a child with ID and/or ASD, there may be needs over and above that of an average family, especially in relation to space. A Scottish survey found that 75% of parents in private rented accommodation said it failed to meet the needs of their child in that it lacked an extra bedroom or a garden/accessible outdoor space. Future needs were also cited as a reason to move in the future with 41% stating that their current accommodation would not meet their family needs in the next five years (Glasgow City Council 2010).

2.0 Methodology

2.1 Research design – an introduction

This study uses a mixed methods approach with the predominant focus on qualitative data (interviews and reflections) backed up by quantitative analysis of data provided by the DOCDSS. An abbreviated version of the methods is presented here with more detail in Appendix 4.

The qualitative element of the study used a case study approach, based on social constructionist ground theory, allowing the research to focus on a 'functioning specific' (Flyvbjerg 2011; Stake 2008; Yin 2012). The study focusses on one service - the Daughters of Charity Disability Support Services - which operates nationally. For the purposes of data collection for this study, the focus was on their services in Dublin 7, 11 and 15.

As DOCDSS provides services to people with ID and/or ASD across the life course, positioning the research within this service provided a unique opportunity to examine the key issues that arise for both families of young adult children and individuals with ID and/or ASD.

Purposive sampling was used to identify specific Service Users who had experience of negotiating the housing market, either as a family with a young or adult child with ID and/or ASD or as an individual with ID and/or ASD.

The data collection centred on open-ended interviews for individual participants – five family members and four individuals who access the services of DOCDSS, both for day-to-day support and in housing. A further six participants, who are Staff Members within the DOCDSS, completed a written reflection based on open-ended questions [See Appendix 5 for details of the research instruments].

2.2 The qualitative element

This qualitative data was supplemented by descriptive statistics from the DOCDSS Electronic Client Record System (ECRS) Database. This data provided a profile of service users in terms of age, gender and housing status as well as statistics on de-congregation and respite care.

In addition, Staff Members gave an overview of numbers in homelessness according to the FEANSTA classification used in this study.

2.2.1 Sampling

The total population of people with an intellectual disability in Ireland represents 1.4% (or 66,611 persons) of the population (Central Statistics Office 2016). Recent housing statistics suggest that the homeless figures for adults in Ireland stands at 10,271 persons (Focus Ireland 2020). However, calculating the population size of adults with intellectual disability experiencing housing difficulty is affected by disputed ways of defining homelessness. The inclusive classification by FEANSTA (FEANSTA 2014) (See Section 1.3b) has been used for this study. The use of this definition (rather than the Irish legislative definition) includes those in inappropriate, insecure and unsuitable housing (and not just roofless) which is of particular relevance to this cohort. As a result, the numbers classified as homeless are much higher.

There is an acknowledged absence of research which involves the direct participation of people with ID and/or ASD on their lived experiences of homelessness and housing difficulty (Durban 2018a; Durban 2018b).The sample size, while small and limited to one Service Provider in the Dublin area, can be seen as an information-oriented selection where participants were selected on the basis of their personal knowledge in this area (Flyvbjerg 2011).

2.2.2 Inclusion and exclusion criteria

In order to address the research question accurately, a number of inclusion and exclusion criteria were applied, such as having the capacity to give informed consent, have ID and/or ASD and an experience of homelessness.

2.3 Recruitment and consent

Gatekeepers play a crucial but often undervalued role in the conduct of social research. In providing access to participants they have to honour their ethical obligations both to their Service Users and their organisations (Singh and Wassenaar 2016). The Gatekeeper for this study was the Social Work Manager at the DOCDSS who oversaw access to participants through one Social Worker and one Co-ordinator of Independent Living at the service. Both individuals have experience of supporting families and individuals negotiating housing issues and the housing market. Recruitment was based on their professional capacity to discern if individuals and families had the capacity to give informed consent and participate fully in the research project.

Participants, if they expressed an interest in taking part, were given a Participant Information Leaflet (PIL) and Consent Form to read and a period of one week to decide whether they wished to participate. After this time, with their agreement, they were contacted by the Research Assistant (RA) to set up a date, time and place that was convenient to them for interview. They were also advised that they could have a member of the DOCDSS team present if they wished for support during the interview.

However, as a result of the COVID-19 Pandemic, (see Section 2.7c) access to individual and family participants was limited to their Support Staff (in Community Residential settings) or Social Workers. Having initially agreed to interview, they were then (in the case of families) contacted by the RA and a PIL and Consent Form was issued by post with a stamped self-addressed envelope (SAE). When the Consent Form was received by the RA a time and date was set up by telephone that suited the participants.

Similarly, where individual Service Users had agreed (in advance of COVID-19 restrictions) they were approached by their Social Worker or Support Staff and asked if they would still like to participate. A PIL and accessible Consent Form was given to staff to read and explain to the Service Users, and on agreement a time and date was agreed for phone interview. Signed consent forms were collected by staff and forwarded to the RA in advance of the interviews.

In both instances prior to interview the research aims and objectives were again explained by the RA and the consent sheet was read out to the participant to ensure they understood what was asked of them. They were also asked to give recorded verbal consent to audio-recording.

2.4 Data collection

Data collection for this research comprised quantitative and qualitative elements and took place in the first half of 2020. Interviews were conducted by telephone with Service Users in the period April to June 2020 and reflections were collected from Staff Members during March and April 2020.

The qualitative elements of the research were as follows:

- Service Users - interviews with 10 participants (5 families; 5 individuals were interviewed but on analysis one was found to lie outside the study criteria, as the individual had been very unhappy at the beginning of their transition but had since settled in well and was socially integrating both on a house and community level. As a result, this data was omitted from analysis leaving 4 Individual Service User participants)
- Staff Members – written reflections from 6 DOCDSS staff members

The quantitative element of the research was as follows:

- Statistical information from the DOCDSS Database
- Statistics on homelessness/homelessness risk compiled by DOCDSS Staff

This provided an overview of the numbers of people in residential services and accessing residential and housing supports from the DOCDSS in Dublin and the Greater Dublin/Leinster area. This information was provided by the (Data Protection Officer) DPO from their ECRS on request from the Research Assistant following ethical approval for the research. The Research Team had no personal access to the Database.

The Social Work team compiled data on individuals and/or families in their caseloads that met the definition of homelessness used in this study over the previous ten years.

2.5 Data analysis and anonymisation

Statistical analysis gave an overview of the numbers of people within the service in Dublin and the Greater Dublin/Leinster area, their current housing status as well as family make-up and supports utilised.

Qualitative interviews were transcribed verbatim and any identifying information was removed. Each participant was assigned an alpha-numeric code and all data was fully anonymised. Participants were assigned culturally relevant pseudonyms for inclusion in the report.

2.6 Data protection and ethical issues

Ethical Approval was sought and obtained from both the DOCDSS and TCD and Data Protection Impact Assessments (DPIA) were carried out for both sites as part of the ethics application. Approval was granted (19.01.2020 for DOCDSS and 03.03.2020 for TCD). All data gathered for the research was held under a rigid system of protection in accordance with GDPR regulations.

2.6.1 Working with vulnerable groups

People with ID and/or ASD are often considered to be part of a ‘vulnerable group’ which is defined as a number of people who share social characteristics that place them at a higher risk of poverty and social exclusion than the general population (Frolich and Potvin 2008). Having an intellectual disability remains a powerful social identity with the ‘fear of difference’ acting as a barrier to full engagement with the wider community (Anderson and Bigby 2016; Beart, Hardy and Buchan 2005).

Homelessness is identified as an under-reported aspect of inequality for people with an intellectual disability (Oakes and Davies 2008) and there is much discussion about research needing to solicit information directly from an individual with a disability about their perception of their life and this is becoming increasingly important (Becker, Roberts, Morrison and Silver 2004; Freedman 2001). Participation in research can be a positive and empowering experience and is especially important in overcoming social exclusion (Abbot and McConkey 2006; Hall 2010).

2.6.2 Explicit consent

In order to ensure that the participants fully understood what was being asked of them, a number of checks and balances were put in place, including the use of process and explicit consent.

2.7 Quantitative data analysis

The restrictions around the time of the study also meant that a physical meeting with the Data Manager at DOCDSS could not be facilitated. However, basic demographics on Service Users were supplied by DOCDSS from their ECRS and analysed by the research team.

The definition of homelessness used by DOCDSS in the ECRS is determined by Statutory context, and therefore limited to those only without a roof over their heads. The data was thus supplemented by the Social Work Team amassing a statistical file from their own individual caseloads, allowing for the broader classification of homelessness used in this study.

Some data that the research team wished to explore but was not available was – age of carer; service user reported reason for threat to homelessness; etc. The quantitative data provided by staff provides a valuable insight into the profile and triggers for homelessness and risk of homelessness and also highlights potential areas for future research and data collection to support service planning and delivery.

3.0 Participant profiles

3.1 Staff members

Five Staff Members from the DOCDSS were asked to give their views on housing and homelessness for people with ID and/or ASD. An additional Staff Member wished to contribute and their input brought the total number of Staff participants to six.

The Staff Members had been working at DOCDSS as Social Workers or as an Independent Living Co-Ordinator for between 12 and 30 years, with an average length of time working in a disability support role for over 20 years.

There were five female Staff and one male. Three of the Staff worked exclusively with families, and two worked with both family and individual Service Users. One Staff worked with adults in the field of Independent Living Support.

3.2 Family service users

Five families who were caring for a family member with ID and/or ASD (being supported by DOCDSS) participated in the study. Three of the five family participants were new to Ireland. The following is a sociodemographic profile of the participants who were the main carer for their family member with a disability.

Table 3.1 Sociodemographic Profile of Family Service Users

Age	Gender	Education	Emp Status	Marital Status	# of Moves	Type of Moves	Length of time Homeless
41-60	Female	Tertiary	Employed	Married	3	Home Acute Hospital x2, Community Residential, Home	1-2 years
61 -70	Male	Post-Primary	Unemployed	Married	3	Home, Acute Hospital Community Residential Home	1-2 years
21-40	Female	Post-Primary Equivalent	Unemployed	Married	3	Private Rented, Family Hub, New Home	3-4 years
41-60	Female	Post-Primary Equivalent	Unemployed	Single	5	Private Rented (x2) Couch Surf (x2) New Home	Under 1 year

Age	Gender	Education	Emp Status	Marital Status	# of Moves	Type of Moves	Length of time Homeless
41-60	Male	Primary Equivalent	Unemployed	Married	5	Private Rented Hotel Family Hub Apartment New Home	3-4 years

3.2.1 Age and gender

Five family Service Users (who are supported by DOCDSS generally and in Housing Services) who were the main cares for their relative with a disability were recruited to this study. Four were female and one was male. Apart from one female participant (who was responsible for her sibling's care) they were all parents to children (or adult children) with ID and/or ASD.

This group of participants ranged in age from twenty-eight to sixty-eight years. Between them they were responsible for the care of ten young or adult family members - six of whom had ID/ASD. Two of these six were female adults (with an average age of 38 years). The remaining four were children were aged between two and 12 years. Of these, one was a girl and the other three were boys.

Three of five the family participants are families that are new to Ireland.

3.2.2 Education, employment and marital status

Three of the primary carers had achieved post-primary (or equivalent) levels of education, while one had a tertiary education and one had completed their education at primary school level only.

One of the primary carer participants was employed outside of the home (but did not have full time care of her sister), while the other four were not working outside the home and were providing full time care for their child or children.

Of this group, four were married and one was single.

3.2.3 Number and type of housing moves

Either they as a family, or the person they were caring for, had moved accommodation between two and five times. As a group, they had experienced homelessness for between ten months and three and a half years,

In the two instances where the person cared for was an adult, these moves were from home to an acute hospital. Their relative was admitted for injury, but could not be discharged home afterwards as their previous homes were unsuitable, and so they remained in hospital until a suitable place could be found for them in a Community Residential House. Both individuals had been homeless for one year.

The families who cared for children with a disability (n=3) had transitioned between three and five times. These moves were from private rented accommodation to emergency accommodation (Hotel, Bed and Breakfast, Family Hub) in two instances. In one case, the family couch-surfed in different friend's houses.

3.3 Individual service users

Five Individual Service Users with ID and/or ASD participated in the study. However, on analysis, one participant lay outside the inclusion criteria, and so the following is a sociodemographic profile of the four participants who met the criteria.

Table 3.2 Sociodemographic Profile of Individual Service Users

Age	Gender	Education	Emp Status	Marital Status	# of Moves	Type of Moves	Length of time Homeless
41-60	Female	Primary Equivalent	Unemployed	Single	8	Home Relative Hostel Community Residential Houses (3) Private Rented (2) Congregated Setting Own Apartment	1-2 years
41-60	Female	Primary Equivalent	Unemployed	Single	7	Home Residential School Community Residential Houses (2) Private Rented House Share Congregated Setting	1-2 years
41-60	Male	Post-Primary Equivalent	Employed	Single	1	Home Community Residential Home (shared bedroom)	Under 1 year
41-60	Female	Primary Equivalent	Unemployed	Single	2	Home Respite Community Residential Home	Under 1 year

3.3.1 Age and gender

Of the remaining four participants, three were female and one was male. They were aged between 41 and 60 years.

3.3.2 Education, employment and marital status

Three of the four participants had achieved primary equivalent school education only. None of these participants were employed (they had all been in receipt of day supports which were not available during COVID-19 restrictions). One participant had achieved post-primary equivalent education and was in supported employment (within DOCDSS).

All four participants were single.

3.3.3 Number and type of housing moves

This group had moved accommodation between one and eight times. These transitions ranged from home to Community Residential Houses, return to Congregated Settings, Respite, Hostels, House Share and Private Rented accommodation.

They experienced homelessness for between eleven and eighteen months. Periods of homelessness under the classification used in this study include prolonged time spent in respite, hostels and congregated settings.

4.0 Quantitative results

The following are results from the DOCDSS (Electronic Client Record System) database providing a Service User profile. Additional statistics on homelessness were provided by the Staff Members based on their individual caseloads.

4.1 Service user profile and demographics

At the time of reporting, there were 1,130 service users availing of services from DOCDSS Dublin and greater Dublin/ Leinster services. Of this group, 51.6% (n=584) were male and 52.2% (n=590) were aged 18 years and over.

Of those aged under 18 years of age (n=540, 47.8%), three-quarters (75.6%) were living at home with both parents while 16.9% were living at home with one parent.

A much lower percentage of those 18 years and over were living at home with both parents (21.9%) or one parent (12.9%). The most prevalent type of residence reported were residential centre (36.1%) and residential community house (25.4%). A small percentage were living independently (1.7%) or semi-independently with supports (1.0%).

4.2 De-congregation

Movement from congregated settings has been minimal with a total of 13 people documented as moving from congregated setting to a community setting between the years 2016 and 2018, with no community moves recorded for 2019 and 2020 to date. However, DOCDSS have been de-congregating since 1991 with the opening of eleven purpose-built bungalows to originally accommodate 110 service users who had been living in a long stay congregated residential setting. As efforts continue to enable people to have more privacy, this figure is now 77. In 2008, a further nine bungalows were built to accommodate 54 services users who had been living in similar circumstances and in 2013 a further six bungalows were built to accommodate 36 individuals. However, these moves are not acknowledged under HSE de-congregation figures because the bungalows are not based in the community.

Delays because of COVID-19 temporarily halted the planned move of three residents from congregated settings this year, with a further three planned for 2021.

The current vision for housing for DOCDSS will be through Marillac, a newly established AHB run by the DOCDSS which will enable the organisation to source a variety of person-centred housing through CAS and other funding methods.

4.3 Respite

Respite is provided by DOCDSS to provide short breaks to both Service Users and their families. This is predominantly provided by a service within DOCDSS called Connect. This service is a social and recreational one, but also responds to the individual needs of Service Users and their families during times of stress or difficulty. The provision of regular breaks can reduce the need for overnight respite and/or residential care. Overnight respite offers a break to Service Users and families often to alleviate high levels of stress, illness and/or medical concerns and to delay breakdown in placement.

Typical allocation of respite is one day per month per person. However, not everyone avails of or is entitled to respite, and individuals and/or families have to apply for the service. Of the 145 people on the homeless/risk of homeless list, just 49 had availed of respite services. Of these 49 people, the number of nights in one year ranged from 1 to 365 with an average respite nights of 46.9 nights. However, one individual was in respite placement for 365 days which equates to an emergency/crisis placement and so could be seen to distort the average. With this removed, the average respite days for Service Users is 12. The age of those receiving respite ranged from 7 to 67 years, with the average age 28 years of age. The profile of those on the homeless/risk of homeless housing list receiving respite is shown in Table 4.1.

Table 4.1 Profile of Individual Service Users at Homeless Risk Receiving Respite

	n (total sample = 49)	%
Age		
0-17 years	12	24.5
18 years and over	37	75.5
Level of ID		
Mild	4	8.2
Moderate	32	65.3
Severe/ profound	13	26.5
Secondary diagnosis		
Yes	46	93.9
No	3	6.1
Country of origin of parents		
Irish	36	73.5
Non-Irish	13	26.5
Family composition		
One parent	11	22.4
One parent & sibling(s)	6	12.2
Two parents	12	24.5
Two parents & sibling(s)	12	24.5
Lives with siblings	4	8.2
Parent (s) Deceased	2	4.1
Other	2	4.1
Employment status of parents		
Both parents on social welfare	6	12.2
One parent on social welfare	11	22.4
Both parents working	3	6.1
One parent working	13	26.5
Retired	2	4.1
Other	11	22.4
Missing	3	6.1

4.4 Staff reported homelessness – including and excluding crisis admissions

Only 3 people were recorded as homeless on the DOCDSS database as discussed earlier (See Section 2.9). Data on homelessness or risk of homelessness is not always shared with the data base co-ordinator. However, DOCDSS has now put in place systems for this information to be recorded by Staff and communicated to the database co-ordinator.

Work undertaken by the Social Work team to compile data on individuals and/or families in their caseloads that met the definition of homelessness guiding the current study in the previous 10 years resulted in 145 individuals/families being classified as homeless or at risk of homelessness with 31 of this group reported as crisis admissions to the DOCDSS service, nursing home or hospital but effectively homeless. If the Irish legislative definition had been used, only three of these individuals or families would have been regarded as homeless or at risk of homelessness.

The criteria used for inclusion on this list included those who had declared themselves (on behalf of a son or daughter) as high priority for the residential wait list, as well as those who were crisis admissions as a result of carer illness or death or the where the carer has refused to take them home. The team also included those Service Users who would have been in an unsuitable environment (e.g. sofa surfing, hostels, other emergency accommodation, hospitals or nursing homes), or in an environment which was physically poor or because of assaults. Crisis admissions are unplanned and may occur due to sudden illness or death of a parent/carer or when they are no longer able to continue to offer care and support to their family member. There is some overlap within the sample of 145 as some families include two siblings with ID and/or ASD, and so everyone is recorded as a case.

Data is presented in Table 4.2 to Table 4.5 on these two groups separately – individuals/families homeless (n=114) and crisis admissions (n=31).

Most crisis admissions were aged 18 years and over (90.3%) whereas there was a more even spread across the age profile of the homeless non-crisis group (54.4% aged 18 years and over).

Moderate and severe/profound were the highest reported levels of intellectual disability for both groups with the majority of each reporting a secondary diagnosis (autism, mental health, physical disability or other chronic health condition).

Table 4.2 Sociodemographic Profile of Staff Reported Homeless/at Risk of Homelessness and Crisis Admissions over a Ten-Year Period

	Total sample n=145		**Homeless (ex. crisis admissions) n=114**		**Crisis admissions n=31**	
Age	**n**	%	**n**	%	**n**	%
0-17 years	55	37.9	52	45.6	3	9.7
18 years and over	90	62.1	62	54.4	28	90.3
Level of ID						
Mild	18	12.4	17	14.9	1	3.2
Moderate	86	59.3	67	58.8	19	61.3
Severe/ profound	30	20.7	20	17.5	10	32.3
GDD/Not assessed	5	3.5	5	4.4	0	0.0
Missing	6	4.1	5	4.4	1	3.2
Secondary diagnosis						
Yes	134	92.4	107	93.9	27	87.1
No	11	7.6	7	6.1	4	12.9
Country of origin of parents						
Irish	100	69.0	76	66.7	24	77.4

Data in Table 4.3 shows that those who presented as crisis admissions tended to come from one parent families (67.8%) whereas the individuals presenting in the homeless (non-crisis) group were more likely to come from a two-parent family (50.9%).

Table 4.3 Family Composition of Staff-Reported Homeless/at Risk of Homelessness and Crisis Admissions over a Ten-Year Period

	Total sample n=145		**Homeless (ex. crisis admissions) n=114**		**Crisis admissions n=31**	
Family composition prior to crisis admission	**n**	%	**n**	%	**n**	%
One parent	40	27.5	21	18.4	19	61.3
One parent & sibling(s)	22	15.2	20	17.5	2	6.5
Two parents	27	18.6	26	22.8	1	3.2
Two parents & sibling(s)	40	27.6	32	28.1	8	25.8
Lives alone	6	4.1	6	5.3	0	0.0
Lives with siblings	2	1.4	2	1.8	0	0.0
Lives with staff	2	1.4	2	1.8	0	0.0
Lives in service	1	0.7	1	0.9	0	0.0
Focus Ireland Housing (20+ yrs)	1	0.7	1	0.9		
Other	4	2.8	3	2.6	1	3.2

Data in Table 4.4 shows a higher proportion of parents in both groups reported relying on social welfare payments (just under half of the homeless group, 43.8% and 38.7% of those linked with crisis admissions), compared with parents working (one or both parents), 29.8% of the homeless group and 22.6% of the crisis admissions.

Table 4.4 Family Employment Status Profile of Staff-Reported Homeless/at Risk of Homelessness and Crisis Admissions over a Ten-Year Period

Employment status of parents	**n**	%	**n**	%	**n**	%
Both parents on social welfare	27	18.6	20	17.5	7	22.6
One parent on social welfare	35	24.1	30	26.3	5	16.1
Both parents working	9	6.2	7	6.1	2	6.5
One parent working	32	22.1	27	23.7	5	16.1
One or both parents retired	5	3.5	5	4.4	0	0.0
Other (including parent RIP, in nursing home)	27	18.6	20	17.5	7	22.6
Missing	10	6.9	5	4.4	5	16.1

Data in Table 4.5 shows that those in the crisis admissions group were less likely to report being on the wait list for local authority housing (n=4), while 45 people (39.5%) of the general homeless category were on this waiting list, with the greatest proportion (12.3%) on the wait list for 8-10 years.

Table 4.5 How long a Family was on the Local Authority Waiting List in Staff Reported Homeless/at Risk of Homelessness and Crisis Admissions over a Ten-Year Period

	Total sample n=145		**Homeless (ex. crisis admissions) n=114**		**Crisis admissions n=31**	
If family were or are on LA waitlist - How long?	**n**	%	**n**	%	**n**	%
6 months to 1 year	1	0.7	0	0.0	1	3.2
1-2 years	5	3.5	5	4.4	0	0.0
2-4 years	1	0.7	1	0.9	0	0.0
4-6 years	9	6.2	9	7.9	0	0.0
6-8 years	7	4.8	7	6.1	0	0.0
8-10 years	15	10.3	14	12.3	1	3.2
10-12 years	6	4.1	4	3.5	2	6.5
12 years+	2	1.4	2	1.8	0	0.0
Family already in LA housing	2	1.4	2	1.8	0	0.0
Other	1	0.7	1	0.9	0	0.0
N/A	96	66.2	69	60.5	27	90.3

4.5 Staff reported reasons for homelessness/crisis admissions

The quantitative data highlights several specific threats to families and individuals that may result in homelessness or risk of homelessness. These are presented in the diagram below.

Table 4.6 Staff Reported Primary Reasons leading to a Threat of Homelessness (n=145)

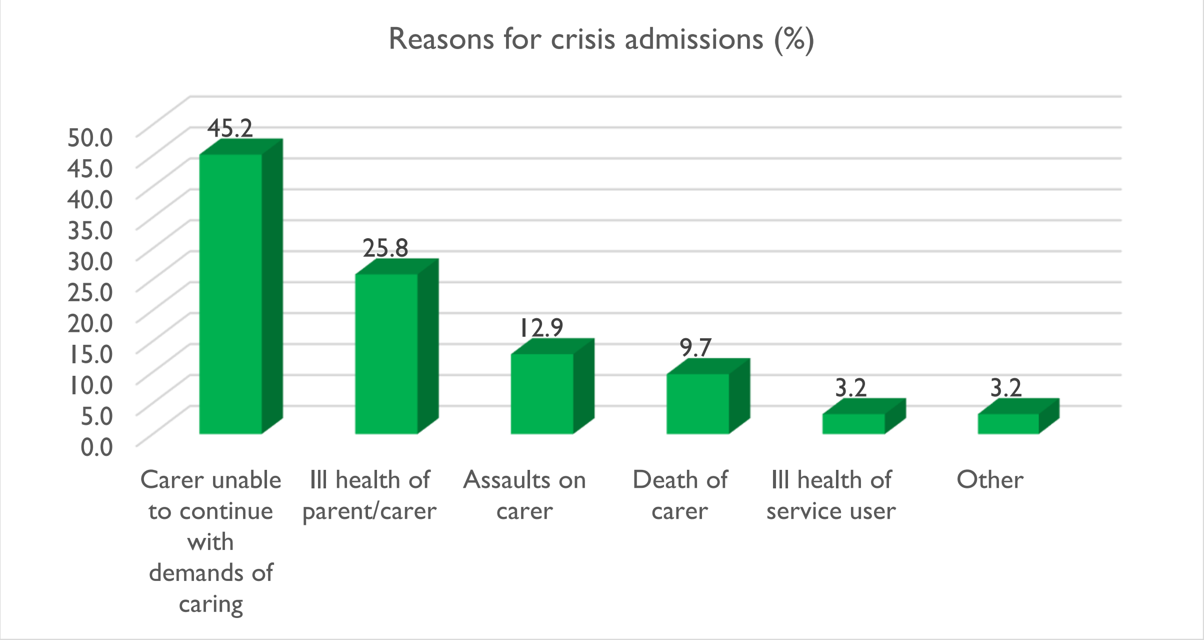
Reason	%
Issues with landlord	21.9
Demands of caring	20.2
House not adapted for disability	12.3
Ageing parents/carer (65+ years)	11.4
Assaults on carer	7.9
Other	7.9
Overcrowding	6.1
Service user wants to move out of home	3.5
Home not suitable (sensory issues)	3.5
Missing	1.8
Relationship breakdown	1.8
Poor quality housing	1.8

The most frequently reported threats to homelessness identified by DOCDSS staff for the service users they were supporting were issues with the landlord (21.9%), demands of caring (20.2%) and house not adapted for disability (12.3%). Other factors which were reported were ageing parents (11.4%) and assaults on carers (7.9%). The next most common category was 'Other' (7.9%) and include financial reasons, parents deceased, coming to Ireland as asylum seekers, lack of placement, not being able to manage at home alone.

The reasons motivating crisis admissions were also recorded. Various factors can result in a crisis admission being made. There is some similarity and overlap between the drivers for homelessness (above) and crisis admissions. The most dominant reason for the crisis admissions are presented in Diagram 4.1 below.

As the graph shows, the demands on the carer (45.2%) and ill-health of the carer/parent (25.8%) were the most frequently reported reasons crisis admissions were made, accounting for 71.0% of all admissions.

Diagram 4.1 Staff Reported Primary Reasons for Crisis Admissions over a Ten-year Period



5.0 Qualitative findings – a summary

This chapter provides the findings of the six Staff Members who submitted reflections on their experiences of supporting people with ID and/or ASD as part of their profession in the DOCDSS as well as the primary care of the five families who use their services and four individual Service Users of the DOCDSS. Diagram 5.1 provides a summary of these findings.

Participants across all groups cited socioeconomic factors as a reason for entering a state of homelessness, most notably an over-reliance on social welfare as a driver for this as well as poor literacy.

Inadequate housing is driven by an over-reliance on the private rental market for accommodation, which, due to a lack of understanding of the needs of people with ID and/or ASD leads to substandard accommodation (including emergency accommodation) and subsequent health issues.

As a result of this dependence on the private rental market, there is little in the way of security of tenure, leading to housing instability, which is further compounded by lack of supports, the changing needs of families as well as behavioural issues which lead to marginalisation.

There is clear evidence that the return to residential services is predominantly driven by over-reliance on private rented accommodation, as well as the difficulty accessing housing (through bureaucracy), marginalisation and a lack of individualised supports.

Diagram 5.1 A Summary of Qualitative Findings from all Participants

Staff Findings

- **Socioeconomic, cultural and ethnic issues**
  - poverty and economic dependence
  - cultural and ethnic issues
  - age and gender
  - family size
  - education and literacy

- **Inadequate Housing**
  - sub-standard accommodation
  - practical difficulties
  - the need for physical space
  - crisis admission
  - children and residential services
  - lack of independence
  - temporary housing

- **Housing Instability**
  - lack of security of tenure
  - absence of services
  - behavioural issues
  - changing needs
  - the implications of instabilty

- **Return to Residential Services**
  - over-reliance on private rented sector
  - bureaucracy
  - marginalisation
  - lack of individualised supports

Family Findings

- **Socioeconomic, cultural and ethnic issues**
  - poverty and economic dependence
  - cultural and ethnic issues
  - age and gender
  - family size
  - education and literacy

- **Inadequate Housing**
  - dependence on private rental market
  - emergency accommodation
  - care crisis
  - regression and behavioural changes
  - psychological ill health and homelessness

- **Housing Instability**
  - lack of supports
  - control, choice and coercion
  - practical issues
  - behavioural issues
  - changing needs
  - marginalisation

- **What is a home?**
  - safe space
  - basic human right

Service User Findings

- **Socioeconomic, cultural and ethnic issues**
  - economic dependence
  - age and gender
  - education and literacy

- **Inadequate Housing**
  - dependence on private rental market
  - emergency accommodation
  - care crisis
  - pyscholological ill health and homelessness

- **Housing Instability/Return to Residential Services**
  - lack of support
  - choice and control
  - number of transitions
  - behavioural issues
  - lack of social connectedness

- **What is a home?**
  - proximity to services
  - social network
  - independence

5.1 Staff member findings

This section provides a qualitative analysis of the reflections provided by the six Staff Members at DOCDSS.

5.1.1 Risk of homelessness – socioeconomic, ethnic and cultural issues

All of the Staff Members (n=6) felt that the pathways into homelessness for people and families with ID and/or ASD were due to a number of specific factors and not just a general reflection of the housing crisis. Many of these challenges were around the socio-economic, cultural and ethnic issues that face individuals and families who have a young or adult child with ID and/or ASD in terms of housing, and as such form a structural pathway to homelessness risk. The sociodemographic findings on this participant group is contained in the Participant Profiles (See Section 3.2 – Table 3.1; Section 3.2 – Table 3.2).

Poverty and economic dependence

All (n=6) of the Staff Members stated that the current high cost of housing and rents experienced in Dublin, coupled with a lack of suitable housing, were placing an undue burden on people and families coping with ID and/or ASD.

Lisa, who works in early services says:

> 'High rents, inability to afford a mortgage and long waiting lists for social housing leave families vulnerable. For families who also have a child with a disability is greater because they also have a need to be near services and may have specific housing needs…the cost of disability is well known. It is often necessary for one wage earner to give up work to provide full time care and so the family cannot afford a mortgage'.

To compound these issues, a Staff Member explains that the stress of caring for a family member with ID and/or ASD means that often they experience more poverty, relationship breakdown, poor health and isolation than their non-disabled peers. Kevin, who works with both families and individuals, describes the difficulty of caring for a child with ASD who can often exhibit disruptive behaviour:

> 'One parent informed me that she has never received a deposit back from a landlord … due to damage her active son with ASD has made in their homes…this parent is a full-time carer thus finding a deposit when she has to move is extremely challenging.'

For individuals looking to live independently, who may have limited education and therefore only access to poorly paid work, if any, they often find that rent is out of their reach, even with financial support as Ellen, who works with individual adults, outlines:

> 'The regulations set by the housing authorities are that a person looking for accommodation on their own could only seek a one-bedroomed apartment…with a rent cap of €600. At the time one-bedroom apartments were advertised at €1500.'

Cultural and ethnic issues

Many families within the service are those that are new to Ireland. Half (n=3) of the Staff felt that families from different cultural backgrounds are often discriminated against when seeking private rented housing by not only the landlord but the neighbours:

> ‘Measures aimed at preventing landlords from discriminating on the basis of being on social welfare or HAP or on racial grounds are not working. Families feel that once their accent is heard or they say they have children, they are put off coming to view.’ [Wendy, Early Years Staff Member].

And even when they do find somewhere to live, communities are not always welcoming. Kevin gives an example of one family he works with who have a child with Autism who does not sleep well and makes a lot of noise at night:

> ‘The neighbours complain…the family do not speak English as their first language. On occasion this anger can become racist in nature…they were harassed based on nationality … but the anger may have originated from their boy being seen as noisy and different.’

He recalls another family who had a very active and noisy boy with ID and ASD:

> ‘The walls of the home were very thin – this led to considerable conflict with neighbours who eventually brought the landlord to the PRTB claiming that he was neglectful of his duties to maintain reasonable peace and quiet in the dwelling.’

Individuals with ID and/or ASD, who may have the capacity to live independently with the requisite support also find that they can be targets of abuse, as Ellen explains:

> ‘One service user told me about all of the hostels she lived in and unfortunately she came across a lot of undesirables who were very abusive. People with ID are vulnerable and can attract the wrong kind of attention.’

Age and gender

Four of the Staff felt that gender and age have a role to play in instigating a pathway to homelessness.

Laura, who works with families, describes crisis admissions:

> ‘Age and illness can be causal factors – if an older parent is suddenly admitted to hospital or a nursing home, then their adult son or daughter requires an emergency placement.’

However, in spite of this level of care, a Staff Member explains that adults living at home with ID are often not provided for:

> ‘They will never get priority for social housing as they are not considered to be in a crisis.’ [Lisa, Staff Member].

The majority of one-parent families accessing services are mothers parenting alone, and this issue came up with more than half (n=4) of the Staff:

> ‘It is usually (but not always) mothers who do not return to work after having a child with a disability because of the medical and care needs of their son or daughter, multiple therapy and clinical appointments.’ [Laura, Staff Member].

This forces them to depend on benefits (if parenting alone) or to have no income at all (if they are not eligible for the carer’s benefit due to their partner’s income).

Kevin maintains that accessing housing is sometimes impossible for single parents as they cannot respond quickly to view lettings when they become available. For some, their child may present significant behavioural or physical impairment that prohibits them from accessing housing. One lone parent with two ‘big active boys each with ID and ASD … could not manage to go out on her own with the two boys, let alone stand in a queue.’ Children with behavioural issues may have no access to school places in their area or experience expulsions/suspensions due to disruptive behaviour, so there is often no free time for carers.

Gender also plays a role in availability of housing/residential services, as Ireland historically has operated segregated service provision:

> ‘Today, older services often have a disproportionate gender mix across their residential settings [which] can limit opportunities for finding the right mix or grouping for some within a region. A young active man may not want to live with a group of older women, yet this might be the only available vacancy.’ [Kevin, Staff Member].

Family size

While difficult for families generally to emerge out of homelessness, especially where there is ID and/or ASD, it is harder still for large families according to half (n=3) of the Staff. Kevin talks of one family with three of their members experiencing disability who faced ‘extraordinary challenges within the private rented sector for many years.’

Family size, coupled with the additional need for space (due to essential equipment or sensory needs), creates even more of a barrier to accessing housing:

> ‘In local authority or private rented a family of even four children can be difficult to house especially where the service user requires his/her own room or space for equipment.’ [Laura, Staff Member].
> ‘Larger families find it extremely difficult to get four-bedroom houses – even families with only two boys and a girl, for example, may need a four-bedroom house. Children with ASD often have behaviours (such as significant sleep difficulties) which mean that they cannot share a bedroom with a sibling.’ [Wendy, Staff Member].

Education and literacy

All of the Staff (n=6) found themselves providing advocacy, bureaucratic and practical help to families and individuals in order to help them to navigate the housing system.

This may be in the form of providing physical support to attend viewings and liaising with landlords – especially with families for whom English is not their first language:

> 'I provide information on accessing housing, especially for families who are new to Ireland and help them to make applications. I also attend Local Authority meetings, especially for non-English speakers.' [Lisa, Staff Member].

Some Staff Members attend viewings with individuals with ID and/or ASD and this can involve a lot of time and resources. Lisa further describes spending six months trying to locate an apartment for an individual Service User:

> 'Landlords were not willing to rent to people on Social Welfare … they were looking for "professionals"'.

However, for many it is having a poor understanding of the complicated housing application system coupled with a lack of awareness of their rights.

Kevin says that most people with an ID and/or ASD encounter difficulties in comprehending, processing and accessing housing and support services:

> 'Literacy and understanding can be a challenge – they may not be able to access the internet or understand and complete long and detailed housing forms.'

He further explains that the application for a residential placement has changed in recent years, with the individual now expected to apply to their local authority for social housing via their Service Provider and the HSE:

> 'This system can be very bureaucratic … many people with an ID may not be aware they can have a say about where they wish to call home.'

5.1.2 Inadequate housing, homelessness risk – structural and personal factors

Already more likely to be at a socio-economic or demographic disadvantage, all Staff Members (n=6) point out that this cohort have a number of housing needs that are over and above those of the average individual or family experiencing homelessness. These needs may be physical and/or environmental and differ according to the needs of the service user.

Additionally, dependence on local authority or private rented housing leads to limited (or no) choice for families and individuals and where accommodation is not available, many are housed in hotels, hostels or family hubs:

> 'Due to the housing crisis, poverty and social policy, many families remain in inappropriate housing with no alternatives…[this] can impact significantly on the health and well-being of all family members.' [Kevin, Staff Member].

Structural factors: sub-standard accommodation

More than two-thirds of Staff Members (n=4) discussed the level of pressure that families find themselves under to accept housing that is offered, no matter how unsuitable it may be, for fear of going back to the end of the list. Laura describes a Mum being offered a new home and asked for a yes or no answer on the day of viewing:

> 'Given that it takes sometimes over ten years on the housing list to be offered a council house, this is like a gun to their heads.' [Kevin, Staff Member].

Families also find themselves in sub-standard accommodation for years, having accepted housing under pressure, leaving them living in unhealthy situations:

> 'The family (who had a child with high medical needs) were allocated a home under the RAS [Rent Allowance Scheme] scheme – it had problems with damp and faulty heating – it took two years for the family to be relocated.' [Lisa, Staff Member].

Laura describes a family living in a bedsit in Dublin where a mother and her child (who has ASD) shared a bed:

> 'In addition to being extremely cramped, the bedsit is also damp and … black mould has been growing on the wall and ceilings…and Mum has had to stop her child attempting to eat the fungus.'

Structural factors: practical difficulties accessing housing

Regardless of whether the individual or family is looking for private rented or local authority housing, they face numerous practical and bureaucratic barriers.

Kevin explains:

> 'The time and resources needed to navigate housing systems is extremely challenging – for those who work time is often already used up attending hospital appointments or meetings.'

Families can also face additional difficulties in attending viewings due to the nature of their child's ID/Autism:

> 'The complexity of having a child/adult with autism, who cannot tolerate noise, queuing, shared spaces, provides its own challenges'. [Laura, Staff Member].

Laura summaries the myriad losses that a family or individual experience as a result of instability:

> 'Families and individuals will have to move time and time again, each time they lose their home, their community, their Staff and all they have even known.'

Personal factors: the need for physical space

Many Service Users with ID and/or ASD have an attendant physical disability, which means that often there needs to be additional space for their essential equipment:

> ‘Children with an attendant physical disability or medical needs require those needs to be taken into consideration. Level access, wide doorways – apartments need to be either on the ground floor or with access to working lifts.’ [Wendy, Staff].

Laura explains that some families, who have children with life limiting conditions may need a variety of equipment including power assisted wheelchairs, high-low beds, ceiling hoists, sleep apnoea and cough assist machines and points out that in the event of a house being limited in size, this can impact on social interaction even within a family setting:

> ‘In one instance, the children can only mobilise in one room in the home (their shared bedroom) or one at a time in the kitchen.’ [Laura, Staff Member].

Kevin talks of a family of four (two parents and two children – one of whom has a significant attendant physical disability) living in a small two-bedroomed apartment:

> ‘This boy needed equipment … wheelchair, rollator and [so on] must be left in school, the family car or a narrow hallway and cannot be used to promote the boy’s physical development and independence at home.’

For individuals living in the family home, the situation is not any better. As service users age, so too do their parents. Grants are available (but limited) and in the private rented sector, often landlords won’t allow the adaptations required. Laura describes an older parent with two adult sons – one very disabled:

> ‘They had no downstairs bedroom or bathroom and her other son would carry the service user on his back to bed…in the morning he was gone to work … so Mum would use a bin liner to bring her adult son downstairs.’

Children with Autism and/or behavioural needs often benefit from having their own space, which can mean a larger house for the family size, which is not always understood by the local authority.

Laura discusses a family of eight living in a three-bedroomed house in the city with one child who had Autism and moderate ID. On return from his day service he would ‘pull his hood up over his head and stick his head in the hot press his need for space was so great.’

Laura recalls working with a young mother, new to Ireland, who had two children with severe ASD:

> ‘They were housed in a fifth floor two-bedroomed apartment. Mum could not open the balcony as she was afraid her son would throw himself over. She

> spent hours out in parks trying to tire him out. Being in a buggy calmed him so she would push him for miles at night to try and get him to sleep.'

Personal factors: crisis admissions

For individual Service Users, there is:

> 'little or no funding being made for supported housing or specialised ID services to provide housing…and this is an issue for adults with ID/ASD are finding themselves homeless due to the death of a carer or inability … to continue care.' [Susan, Staff Member].

This issue arose with two-thirds (n=4) of the Staff Members. This invariably leads to crisis admission to services:

> 'Older ageing parents who are exhausted and unable to deliver the physical and emotional care required – or just unable to cope due to ongoing assaults. Many parents/carers reach a stage of being unable to continue caring due …and some Service Users become ill or have care needs that ageing parents cannot manage.' [Laura, Staff Member].

This can lead to Service Users being placed in inappropriate settings, such as medical or psychiatric hospitals, nursing homes or in respite for long periods of time. The sudden death of a carer or parent can leave the Service User jettisoned from the family home, dealing with grief over the loss of both a parent and their home while trying to negotiate settling into unfamiliar surroundings with people they do not know.

The issue of ageing parents or carers emerged in two-thirds of the reflections (n=4) and Laura describes two instances where the main carer (Mother) was taken into hospital and was no longer able to care, instigating a crisis. She relates that one Service User [in her early 40s] ended up in a Nursing Home outside her catchment area and another [in her late 50s] lived in respite for nearly a year.

Another Service User, (early 20s) with mental health issues as well as ID and attendant physical disabilities had been placed in a psychiatric unit in a general hospital, while another man in the same age bracket could not be discharged from a general hospital for over a year due to an increased physical disability.

Kevin points out that getting the right placement may take a very long time:

> 'The family experienced crisis following their Mother's death … and as a result their brother lived in a respite setting for over a year. The family fought hard for many years to access a house for their brother with other young men so that he could continue to enjoy a good social mix.'

Laura describes one instance where an individual, following a family breakdown, spent ten months dividing his time between sofa-surfing and respite care.

Personal factors: children and residential services

Two of the other Staff Members also talked about families, so overwhelmed by the lack of support services for their child, they found themselves completely unable to cope any longer and as a result of crisis, their children had been admitted to residential care. Laura refers to one adult who now lives in a single occupancy high support unit:

> 'Amazing how many staff and resources he requires and receives now, and his poor family were expected just to cope.'

Kevin points out that residential placements for children are extremely rare:

> 'Within our Dublin Service with approximately 600 children, there is one residential house for three children. If a family are in crisis there are limited options … so a child can drift in a short-term residence with a transient population for a long period.'

He describes one Mother who was admitted to hospital and unable to care for her children on her return:

> 'They remained in a respite setting for the next two years – greatly reducing the availability of respite support to other families in need.'

He cites another case, in which a teenage child with a severe intellectual disability, (as well as an attendant physical disability and a medical condition) who:

> 'could not be dropped off [from school] as his Mother had reported that she could no longer manage to care for him. As per Department of Education Transport policy, the child was brought to a Garda station. No respite, children's home or foster family [were found that would suit his needs] and he was admitted to a general hospital and placed on an adult ward where he remained for a number of weeks.'

Personal factors: lack of independence

In other instances, adult children with ID and/or ASD continue to live at home because they do not have the support of their parents to live independently:

> '[This man in his late 20s] would like to live in a house with his peers. He is very independent ...Mum is anxious that he would not be able to live independently and has not supported this application so [the] documentation required has not been made available. Many of our young adults living at home express a wish to move out and live with peers … they report having no social life, no access to friendships and relationships or meaningful activities because they are dependent on parents … who may be dismissive of their wishes, [not seeing this] as a viable option.' [Laura, Staff Member].

Personal factors: emergency accommodation

Families and individuals who become homeless (mostly as a result of a notice to quit from their landlord) present themselves to their Local Authority as homeless. This leads, in most instances, to them finding themselves housed in temporary emergency homeless accommodation. Such accommodation can take the form of a hotel room, hostel or shared family hub. Their only other option is to share with family/friends (couch-surfing).

All (n=6) of the Staff Members felt that such accommodation was unsuitable for individuals and families with ID/ASD, pointing out that these solutions were often noisy and overcrowded (n=5) leading to regression for children (n=5) and mental health issues for parents (n=4).

Personal factors: overcrowding and noise

Lisa refers to hostel accommodation as ‘horrific’. Pointing out that in many hostels and hubs, kitchen and dining areas are shared:

> ‘It may be impossible to prepare a meal and supervise a child (who could be hyperactive, loud etc) and sit in a shared dining room.’

Where diet is important, families often find themselves unable to prepare meals (if they are living in a B&B or hotel) or while living in a ‘hub’ experience limited kitchen opening times.

Laura, describing such emergency housing options as ‘horrendous’ outlines one family under severe pressure. Both parents and five children (two of whom have a disability) are living in one room. They depend on the school to provide meals for the children as they experience dysphagia (difficulty swallowing) and are at a high risk of choking:

> ‘[The children] are not toilet trained as the family only have access to one toilet, so it is easier to keep them in nappies.’

Personal factors: regression in children

The level of overcrowding and noise, especially for children with ASD, often leads to significant regression in behaviour. Laura recalls another family who had a child with ASD and who found the situation unbearable:

> ‘He began soiling and Mum only had a washing slot twice a week. He was awake most of the night.’

Lack of outdoor space is also a problem, and she describes another family who lived in a hub with no real access to a garden:

> ‘The paved back garden was accessed via seven steps and used as a smoking area by other residents … [the lack of garden space meant] baby was unable to learn to mobilise and crawl.’ [Laura, Staff Member].

Personal factors: psychological health

Trying to support individuals and parents in these environments is also challenging:

> ‘Meeting with a parent in private is difficult.’ [Lisa, Staff Member].

The fact that temporary accommodation is often out of the catchment area for established services means that their supports are often too far away or not available as they are ‘out of area’:

> ‘It is extremely difficult to sustain even for the most well-equipped family. Unfortunately, it appears that temporary settings can become home for months and longer for families who often do not have access to essential amenities throughout this time.’ [Kevin, Staff Member].

Four of the Staff talked about this strain leading to serious mental health issues for parents and individuals:

> ‘People with ID need consistency and security and living in accommodation that may have a lot of people coming and going would have a profound effect on them…this can [affect] a person’s ability to cope and understand their situation.’ [Susan, Staff Member].
> ‘Families are extremely resilient generally, but depression and anxiety and sometimes even suicidal ideation is not uncommon under these circumstances.’ [Lisa, Staff Member].

Half of the Staff Members (n=3) also expressed concern about the effect on siblings of a child with ID and/or ASD in such confined spaces, where they can experience physical abuse and lack of sleep as a result of their sibling’s disability. They describe the emotional and social impact on siblings around sleep disruption, destruction of property and lack of privacy:

> ‘His two brothers have each attended their GP and counselling. They report not having any space as there are constantly strangers (various carers) in their home … they have to be vigilant … [there is] constant noise in the home [making] studying difficult and their parent’s time is always taken up with the care of their brother.’ [Laura, Staff Member].

Personal factors: individuals

Temporary housing options for individuals are even more limited, and they tend to be referred to hostels only as single users. Ellen recalls supporting a service user at her Local Authority, having spent six months trying to find suitable accommodation for her:

> ‘We were sitting at a hatch when the guy told her that her only option was to go to a hostel, he also said “I wouldn’t recommend it”. Hostels are not appropriate for people with ID who are already vulnerable.’

5.1.3 Challenges to housing stability – structural and personal factors

Lack of security of tenure

The lack of funding and/or policy to provide secure social housing means that there is an over-reliance on the private rental sector which leads to insecure tenancies according to all of Staff (n=6). Many of the families and individuals that the Staff work with have become homeless having received notice to quit by their landlords:

> ‘Most families I have worked with who are homeless or at risk of homelessness have been in private rented accommodation and been given notice to quit because the landlord needed to sell/ renovate or make the accommodation available to a family member’. [Lisa, Staff Member].

Ellen, who works with Individual Service Users describes an innovative approach taken by the DOCDSS to independent living, using funding from an NGO which is tasked with developing better ways to support disadvantaged people to live better lives in their communities. This involved a considerable amount of time in staff training for 12 DOCDSS Staff Members and involved the use of the model of Social Role Valorisation (SRV) which aims to change the lives and perceptions of people who are disadvantaged because of their status in society:

> ‘We applied for, and received, funding [from an NGO] to support individuals to live a better life in their communities using SRV as a practice model. We used a “discovery process” which involved working with one person at a time and helping them to define what they needed to be successful in their desire to live better lives. Of those that participated, all six Service Users managed to get an apartment renting privately in the area, in spite of a very challenging housing market. However, after living in appropriate accommodation for five years three individuals were made homeless because the landlord was selling the property. And while two have since been rehoused, it was through purchase of a house using CAS funding in one instance, and Local Authority housing in the other. At the time of writing the third Service User is waiting on news about Local Authority housing. Homelessness was an extremely difficult time for the individuals involved as they had become so safe, secure and familiar with the area.’ [Ellen, Staff Member].

Absence of services

The majority of Staff Members (n=5) found that there were major barriers to locating individuals and families near to both ID services and services generally, and that housing instability often led to lack of services:

> ‘We know that there is a huge crisis in housing, but for people with ID this is further compounded because there is very little appropriate housing to meet their needs. There is little or no funding being made for supported housing or specialised ID services to provide housing.’ [Susan, Staff Member].

In the absence of such specialised services, being able to remain in an area where a family or individual with ID and/or ASD is already linked into services is crucial.

Wendy adds that access to services is particularly important for individuals and families noting that there is a fear around moving out of a catchment area and subsequent loss of services:

> 'Services are patchy in their provision and over-subscribed so moving area is a big risk – waiting lists can be very long so people opt to stay in a service if they have one.' [Wendy, Staff Member].

Lisa discusses a current case where the house is allocated outside of the catchment area, and the child has been referred to another disability agency:

> 'This has a year-long waiting list – the child is only 20 months old so any break in service may have serious implications for the development of the child.'

The supports established when an individual or family first links in with their Staff is crucial but is not taken into consideration by local authorities when offering accommodation.

Behavioural issues

However, more than two-thirds (n=4) also point out that landlords evict because of damage to property or complaints by neighbours due to challenging behaviour by a child with ID/Autism:

> 'Some children may have behaviours others find difficult. They may be noisy, impulsive, agitated or even aggressive leading neighbours to complain that their own children cannot sleep.' [Wendy, Staff Member].

Laura says that such issues can lead to endless moves, in cases such as the one she describes:

> 'Her son has ASD and significant eating and sleeping issues. Mum has found it difficult to renew leases as her son is extremely loud, especially at night as he doesn't sleep. Also, his behaviour impacts on household items being broken, door and walls being damaged. This has caused her to move from tenancy to tenancy.'

Wendy says that there is an ever-present fear as a result of behavioural issues:

> 'Routine landlord visits can be dreaded as they may expose [damage] … or the house has unusual features such as no unnecessary furnishings. Minor modifications [such as additional locks on doors, windows, gates] may not be allowed. Consequently, relations with landlords can be fraught, and there is obviously a huge power differential which can magnify the threat experienced.'

Changing needs

As adults with ID/ASD age, they often develop additional needs – such as those driven by mobility issues or dementia and this can lead to housing instability as their current living situation, even in Community Residential Settings (CRS) may not be adaptable or funding may not be available to carry out such work. Kevin points out that there are few purpose-built environments for people with ID and/or ASD and dementia in Ireland and those that are have long waiting lists. Adults with ID and/or ASD and significant challenging behaviour require bespoke settings to match their needs. He points out in 2013 and 2014, the DOCDSS opened two Dementia-specific support services in response to this need, and the current strategy of the organisation is to expand these.

Laura explains that most CRS housing is typically two-storied and that this impacts on their ability to continue to mobilise as they age:

> ‘Advancing stages of dementia and a decline in mobility is often one of the main reasons [that] they have to leave their community home, but every effort is made to allow them to age in place. They often end up sleeping downstairs in the living room as a temporary measure [in order to facilitate ageing in place] … which is not ideal or fair on their peers as the living room becomes unavailable.’

Laura explains that limited funding, alongside higher demand for residential placements had led initially to many Service Users sharing rooms, which created difficulties as they aged. The goal to reduce to single occupancy rooms was a strategy employed by DOCDSS over a number of years. This has resulted in the number of shared rooms reducing from 25 to just three in the DOCDSS, brought about mostly by a combination of Service Users dying, as well as provision of house purchase or extensions to facilitate individual rooms.

For families with children with ID and/or ASD their needs tend to be ‘not static but change over time, situations and environments.’ [Kevin, Staff Member].

He elaborates, saying that often needs can be quite nuanced, but there is little understanding of this within the housing system:

> ‘Environment and a capacity to make necessary adaptations for changing needs can be crucial for families caring for a member with a disability.’

He adds that while they may have a roof over their head, they experience difficulties in adapting it to accommodate changing needs. This is often a bureaucratic difficulty which is seen to be compartmentalised and where family knowledge and experience is not heard.

5.1.4 The implications of instability

This sense of threat of moving, and actual constant moving has implications for both individuals and families:

> ‘Parents, and sometimes children, can experience significant trauma [in response to this threat]. Often parent’s reserves are already depleted by the daily battles they are engaged in, and there is little respite of any kind available

> to them, so their resilience can be stretched quite thin.' [Wendy, Staff Member].

Constant moving leads to stress and places a financial and emotional toll on families:

> 'If families do manage to access [temporary homeless service] this may be far away from children's school communities and essential services that it is just not possible to sustain. The financial cost for families can have a knock-on effect across all other areas of family life while the practical and emotional toll can also have a lasting impact on family wellbeing.' [Kevin, Staff Member].

> 'It is not a good idea as moving is stressful for any of us, let alone a person with ID/ASD. If they settle and come to like the place it can cause huge trauma to have to up and leave again.' [Ellen, Staff Member].

> 'The majority of our service users require routine, consistency and familiarity in order to function.' [Laura, Staff Member].

5.1.5 Return to residential services – structural and social factors

The challenges encountered in supporting a person in moving from a residential setting or community residential services to independent living are numerous. However, the single greatest factor is in over-reliance on the private rental sector, cited by all the participants (n=6) leading to individuals finding themselves either back in residential services, in respite or even less suitable accommodation.

Structural: over-reliance on the private rental market

As outlined earlier, of the six individuals who successfully made the transfer to independent living, three at some stage became homeless as a result of notice to quit their private rented accommodation. In the absence of finding alternative accommodation (due to high rents or lack of one-bedroom apartments) they found themselves having to present as homeless to their Local Authority:

> 'This was something they were very scared about and one person thought she was going to be on the streets – another thought she would have to live in a hostel and she was very frightened.' [Ellen, Staff Member].

Finding alternative accommodation proved impossible and they had no option but to move back to the organisation temporarily. Ellen says:

> 'They were devastated – they had a roof over their heads, but it was far from appropriate.'

According to Ellen, having lived independently for a number of years (even in challenging circumstances where she was far from transport links) one Service User found herself suddenly homeless and back in the physical location of a congregated setting, although living independently within that. Another Service User had lived in shared accommodation until the landlady became ill and she had to move out. She is now back in a similar situation as that just mentioned.

Some offers of accommodation are simply not suitable for people with ID and/or ASD who are already vulnerable and often this is not taken into consideration by Local Authorities:

> 'She received a call to say they had [an] apartment but it also housed young families who had difficulties … there was drug use and very young kids who tended to go in and out of other people's apartments.'
>
> 'There are challenges in supporting someone to move from a residential setting where they had staffing 24 hours a day – the criteria to live successfully with limited supports is that they feel safe.' (Ellen, Staff Member).

Structural: bureaucracy
There is a high level of bureaucracy involved in accessing the housing market, much of which is beyond the capacity of an individual with ID and/or ASD who may have limited literacy skills according to Ellen:

> '[They don't know] how the systems work – they are unable to read because they have not had much access to education.'

Structural: marginalisation
Ellen also talked about marginalisation of such individuals:

> 'In some cases, they are viewed as unable to live with other members of the community. [They are] frowned upon. Sometimes it's how they present themselves – in the way that they appear or the way that they speak. They don't always know how to express their needs appropriately. This in turn can mean that they can be offered a place that does not meet their needs but find themselves going back to the end of the housing list for stating that the offer is unsuitable without perhaps being able to explain why.'

Structural: lack of individualised supports
There is a high level of support needed for individuals to help them to manage the transition from residential to independent living, and the majority (n=5) of the Staff Members find themselves helping to navigate housing system, preparing documentation as well as assisting them with budgeting, finances, paying bills, shopping, negotiating with landlords and generally helping them to settle into the community.

Laura explains that there is serious pressure on services to de-congregate due to policy (A Time to Move on From Congregated Settings):

> 'There is nothing or nowhere to move to. For many … a congregated setting has been their home all their lives. So, in their 70s and 80s it is expected that there is a house in the community that will meet all of their physical, medical and emotional and social needs.'

She continues that not only are they expected to adapt to this new environment, but also that existing residents in community homes will want them there, and that the community will be able to welcome them.

Lack of support services for independent living can lead to social isolation and loneliness – for example if an individual is living in an area far from family/social connections with a poor bus service. Laura describes the effect this level of marginalisation has on a Service User:

> 'He is in supported employment…he is a very bright, articulate and able young man who would identify as his main concern his loneliness and social isolation.'

She reports that another young man, who has been unable to get supports from staff near to his own age 'verbalises that he is in absolutely dire straits of loneliness' and having recently received a notice to quit from his landlord could not find an alternative one-bed apartment in the area (close to family and services).

5.1.6 Potential solutions

National policy

When asked what they felt would be helpful to people with ID and/or ASD in overcoming these issues, all admitted that there was no one simple solution. However, several of the respondents (n=4) felt that greater levels of funding would help, especially if it was targeted towards more suitable accommodation for this cohort and was supported by National Policy:

> 'There needs to be National Policy with proper funding channels for adults and children with ID/ASD so that they can have appropriate housing and choice within the sector to meet their needs.' [Susan, Staff Member].

Reducing instability in housing

The lack of security of tenure led Staff (n=4) to suggest that more could be done in this area:

> 'It would be useful to have access to a database of available accommodation suitable for their needs. Maybe landlords could offer their accommodation on a disability specific website … a slightly higher HAP payment [would act as] an incentive.' [Lisa, Staff Member].

Ellen agreed and suggested a specialist housing authority that looked at the needs of people with ID and/or ASD on a National Level across the life course.

Improved knowledge base

Two-thirds (n=4) also felt that there was a need for greater education around the needs of this group with regard to the type of accommodation needed and greater liaison between Services and Local Authorities:

> '[We need] acknowledgement by the Local Authorities of service users' environmental and space needs (especially around ASD) so that they can

> discontinue offering inappropriate unsustainable housing, and an acceptance that families have a right to refuse on the basis that the accommodation is unsuitable [without going back to the end of the list].' [Laura, Staff Member].

User and community involvement

Finally, Kevin, admitting that it was a complex issue, summed up the feeling of half (n=3) of the Staff in that the voice of the people central to the issues (individuals and families) and their communities is not being heard:

> 'I believe that more engagement with families and their communities may help finding answers … advocacy, information sharing, consultation, training and research can all help. As a society we need greater awareness and dialogue on the needs of our disabled citizens and how we as a community can work together to value all members and ensure a good life for all. We need … alternative models of housing'.

5.1.7 What is working well?

Staff Members were asked about what positive intervention strategies and best practices existed within DOCDSS to result in good housing outcomes for people with ID and/or ASD and their families.

Responding to current and future needs

The recent establishment Marillac as an independent Approved Housing Body was of particular importance to Kevin. He explains that this change will not impact on Service Users current living arrangements but that it is important for the future if housing needs change as they will be linked in with DHPLG and the local authorities. Community residential properties will be assessed by the local authority and registered with the Residential Tenancies Board. This also means that individuals will complete a housing application, go on the housing list and receive a housing reference number:

> 'The establishment of Marillac is opportune and will help to address future social housing needs for this group. Such a housing body can bring together individual needs, housing and supports and foster greater understanding. In doing do, it can tackle many issues. Such developments reinforce … that in many areas we are on the right track and that all the work that has gone into establishing an AHB has been worthwhile and responsive to emerging need.' [Kevin, Staff Member].

Laura is especially cognisant of the ageing needs of Service Users around health issues and in particular dementia, which she notes will be both an on-going and increasing issue in terms of ageing in place:

> 'Dementia is a critical issue for the DOCDSS given the age profile of the population and it will continue to be an increasing concern in the years ahead. Advancing dementia symptoms have proved challenging, and there were no facilities to support people at mid-stage dementia presenting with Behavioural

> and Psychological Symptoms of Dementia (BPSD) that did not involve a move out of home.
>
> In the early 2000s, the DOCDSS recognised that there was a need to set up a specialist dementia home to support people with such needs, and we set out a Strategic Plan in Dementia which laid the foundations for two (Award winning) state-of-the-art facilities, which opened in 2013. These homes use best practice principles, guided by international consensus and opinion on providing optimal care while minimising stress and promoting quality of life for its residents. All of the staff working there are confident practitioners and are dementia aware.' [Laura, Staff Member].

Person centred care, SRV and empowerment
For Ellen and Lisa, the DOCDSS commitment to the SRV model of practice means that constant communication around the needs and desires of the individuals and families with whom they interact allow them to support the achievement of those wishes through advocacy initially and ultimately to independence.

Ellen cites the example of a Service User who had been in private rental accommodation for three years and then given notice to quit:

> 'This Service User was then homeless and returned to the congregated setting, although living there independently in this environment with their own support staff. The DOCDSS looked into purchasing this previously rented property and put in an application for CAS funding. This was successful, and the property was purchased a year later. This Service User now has security, their rent is affordable, they have their own lease and tenancy agreement with Marillac housing association.' [Ellen, Staff Member].

Ellen also describes the use of the Personal Care Plan which is used in DOCDSS and allows people to have the opportunity to express what it is they would like their lives to look like. This can take many forms and people have gone from sharing bedrooms to having their own room or even sharing an apartment with a friend:

> 'Two people who had grown up together but were living in separate community houses asked, as part of the PCP if they could live together. Three years ago, we were able to obtain an apartment for them and they have lived together since. Their lives have changed for the better in every way.
> The DOCDSS does their best to offer those we support to live their best lives, but this is often fraught with difficulty as we have had to rely on external agencies for other support around housing.' [Ellen, Staff Member].

Wendy notes that often their role is in bridging the gap between what those external agencies (often housing bodies) understand around regarding the impact of disability on housing need:

> 'A young child with complex needs caused some structural damage to a house (which belonged to a housing association). The housing association stated that they had never seen that level of damage before and as a result the family felt judged and misunderstood and this resulted in an adversarial relationship with the housing body. The family were told their tenancy would be terminated if they did not carry out repairs, which was beyond their financial capacity. Working with the housing body involved conflict resolution and an educative piece on why the child's behaviour was so "destructive". Fortunately, the housing body representatives were open and committed and a resolution was worked out over a number of months. Had we not all worked together, it could have had a very difficult outcome.' [Wendy, Staff Member].

Lisa points to how important cross-system collaboration is around housing, especially where families are new to Ireland:

> 'Many of the families I work with often have come here as asylum seekers or migrant workers with little knowledge of the Irish system and sometimes having suffered severe trauma in their country of origin. While I have no control over the housing list, in general I act as facilitator, supporter and advocate in helping them to negotiate the system while they wait for their forever home.
>
> In my experience, the people who do best in this space are those who, in the absence of family and social connections, have good experiences with other support services, be they voluntary, NGO or statutory. Of most importance is to empower people with the knowledge, skill and confidence to self-advocate effectively.
>
> It is all in the relationship I am able to build with individuals and families and this takes time especially in the case of someone who has no reason to trust others. As a specific example, a family who have recently been housed and are happily now setting up home, had the confidence and endurance to persevere in very difficult emergency accommodation for years because they had a really clear idea of what their family needed and their opinion was supported, even though there was a pragmatic option which wouldn't have been a permanent solution. In this case it was important that the family viewed themselves in the role of "citizen" with rights and responsibilities rather than "victim" and that others working with them also viewed them in this way. This is what Social Role Valorisation means in practice.' [Lisa, Staff Member].

5.2 Family service user findings

The following is an analysis of the five family Service Users who participated in this study as reported by the primary carer.

5.2.1 Risk of homelessness – socioeconomic, ethnic and cultural issues

Economic dependence

Note that the sociodemographic findings on this participant group is contained in the Participant Profiles (See Section 3.2 – Table 3.1).

Two of the families with adult children were of Irish origin, and a further three were families who were new to Ireland. Of these three families, all had been in Ireland for more than ten years. In one instance, where there was a married couple caring for their child, the Mother did not have sufficient fluency in English to complete the interview, so the father participated instead.

They had all sought, and been granted, refugee or asylum status.

One mother describes living in Direct Provision when she first arrived:

> 'I was in [Direct Provision] and it was hard there being in asylum generally but not being by myself – you take it as everybody's problem that way and the system it was fair enough.' [Nadia, Mother aged late-40s].

Age and gender

For all of the family participants (n=5) the mother had been or is the primary carer for their child/adult child. One participant, who has been caring for her daughter since birth explained:

> 'She needs 24/7 care … from the time she wakes up she needs someone to wash dress her – she doesn't do any of those things herself. She doesn't have any speech, her mobility got worse as she got older. She has a wheelchair now and a walker for getting around. Her eyesight isn't great.' [Maria, Mother, talking about her daughter aged mid-40s].

> 'Dad is almost 81 now and I suppose he would have just been used to my Mother having you know the primary role in … care and meetings with either school or the day service that she was attending my mother kind of would have had the primary role…to a greater extent than my dad would have been.' [Helen, speaking about her sister, who is in her early 30s].

Family size

Families ranged in size from 2 children to four children, with an average family size of 2.8 children.

5.2.2 Inadequate housing and homelessness risk – structural and personal factors

Structural factors: dependence on private rented accommodation

Three of the five family participants became homeless when their landlord issued them a notice to quit from their private rented apartments. Failure to find alternative accommodation saw them resorting to emergency family accommodation (Hotel or Family Hub) and in one instance to couch-surfing.

Aleeki, married with two children under 10 (one of whom is totally dependent for all of her care needs) describes spending six months trying to find a new home to rent for himself, his wife and two daughters:

> ‘Even if you work you can’t afford to pay the rent because it was a lot of money like to pay the rent.’ [Aleeki, Father, aged mid-40s].

In a further two instances, the rented home that the family were living in was already too small to accommodate their growing family needs – and they were served notice to quit. Abeke, who is married with three children – two of whom have special needs, talks of similar difficulty:

> ‘My husband … he was staying in a studio apartment when … I joined him with my son … and when I had my second son when I was pregnant, and we were trying to look for a bigger place to stay.’ [Abeke, Mother, aged late-20s].

Nadia, who is a single parent with three children, one of whom has special needs recalls how difficult it was:

> ‘It’s very hard. They are not very accepting to give a place. You find that there are no houses. Every time I call, I called and called I wouldn’t even get a place, not even for a landlord to accept … rent allowance and then most of them are very high above my amount. So it just became impossible for me to find another place.’ [Nadia, Mother, aged late-40s].

Personal factors: emergency accommodation

Having failed to secure a rented property, two of the families were referred to Hotel or Family Hub emergency accommodation. In both cases, the family stayed there for more than three and a half years.

One further parent refused emergency accommodation and opted to couch surf as moving out of the area would have meant losing the place her child (who has ASD) had at school.

Each of these temporary solutions gave rise to numerous issues, including concerns around access to normal family routines, lack of space leading to regression in behaviours and serious mental health issues for parents.

In all three instances, families were accommodated in one room. One family of four stayed in a Hotel for two and a half years, then a Family Hub for a further 10 months; one family (of 5) stayed in a single room in a hub for over three years. One family (of four) stayed in different friends’ houses for ten months:

> ‘In one room like it’s very hard for family. For any family. Without if you have a baby with – like your baby sick. Any family to stay in the one room for four people is very difficult.’ [Aleeki, Father, aged mid-40s].

Abeke describes additional support from a family homeless charity helped to get additional space for her son with ASD:

> ‘We were in one room. He wasn’t coping very well…it was just too much for him. So they gave him another extra room just to make it for a sensory room

> for him and you know a play room for him where he could go if he was getting too frustrated or anything – we put in loads of toys and everything in there for him he played for hours.' [Abeke, Mother, aged late-20s].

Personal factors: loss of normal family routines

There was no access to cooking facilities in the hotel where Aleeki and his family stayed, and he talked of what this meant for the care of their young daughter:

> 'We have to look after her [it] is not good for her to have bad food in the hotel or restaurant … for us is ok but for her we think it's not good. You don't know which food you going to [get]. At that time, it was very difficult so we had to go for our friend to ask them to cook.' [Aleeki, Father, aged mid-40s].

Equally, Abeke and Nadia struggled with sharing a kitchen with other people in a Family Hub where cooking times are set and limited. Abeke explained that there was no suitable dining area in the hub that could accommodate her child with special needs:

> 'When we were in emergency accommodation, when you cooked you had to bring food to your room and eat. No dining room. The whole family would have to eat in the room.' [Abeke, Mother, aged late-20s].

Shared facilities, such as washing machines and fridge space also led to difficulties where large numbers of families were sharing the same limited facilities:

> 'I [am]always clean and I always buy things for my kids that you can't put it in the room – you need to put it in the fridge – but if there is one fridge and maybe 15 or 16 people using it …[it leads to] arguments.' [Abeke, Mother, aged late-20s].

Personal factors: regression and behavioural changes

The lack of space in temporary accommodation led to the children with disabilities experiencing behavioural changes and unable to progress with essential exercises.

Nadia talks about couch surfing, sharing with another family. She has three boys, one of which has ASD, and they all shared a room in the house of a family friend. This situation did not work out, however and they moved to another house after a few weeks. She talks of the effect on her son who has ASD:

> 'My son's behaviour became something else. He was a child I did not know. The whole year was a problem and the school almost wanted to terminate him because of this … and so the special unit, imagine, if they had thrown him out what were we going to do every day? The school could not even take the few hours.' [Nadia, Mother, aged late-40s].

Nadia resorted to leaving her friend's house early every morning and staying out all day:

> 'I was staying out the whole day … my son cannot stay – because he is crying to go home – so we are running to go to the home where we have lived just to show him that we can't – that it is closed – that was something we were doing every day. I would have to go and show him and let him understand that we can't go back to the house then we go to the park and then we go round, round, round.'

The lack of space for equipment and exercise meant that Abeke could not do the essential physical exercises with her child:

> 'My son, the one with Autism, when I go to the (specialist) they just say to me he need to have work – with his walking – they just give you some things to do and then there's some equipment that you need to buy but because there is nowhere to put that… he wasn't meeting his milestones I know they have all these services to help with walking, with talking and everything but when I go to the physio sometimes I mean – this is what you're supposed to be doing with him but where am I going to put all the things they ask me to get?' [Abeke, Mother, aged late-20s].

Personal factors: care crisis

In two instances, homelessness came about as a result of a care crisis. In both cases, their adult child and sibling had sustained injuries which reduced their mobility further. One participant describes her father, in his early 80s, trying to care for his daughter who had both an ID and mental health issues:

> 'He started to find taking care of her extremely stressful … and he started then having health problems of his own.' [Helen, Sister, aged early- 40s].

When his daughter broke her ankle, both were admitted to hospital at the same time – he with suspected heart issues.

A Mother describes her daughter, mobility already limited, who fell and broke her knee and was admitted to hospital. A combination of their own age, her daughter's increased care needs and the unsuitability of their home, led them to look for a residential place:

> 'We were looking … for full time residential care because we weren't able to care for [her] anymore. [She] probably would have been more of a danger coming home because I have no downstairs toilet I have only an upstairs. I have only a small home with no way of putting a bed downstairs for her. She can't do stairs anymore. She fell down three lots of stairs already three different times.' [Maria, Mother, aged late 60s].

This led to both adult children remaining in an acute hospital/medical facility for over a year each until alternative accommodation could be found that could facilitate their needs. Helen describes her sister's social interaction while in the hospital as extremely limited, as the majority on the ward were older people with dementia and Alzheimer's disease:

> 'When I go in you know she's walking up and down and she's saying hello to this person and hello to that person and you know … she can't really speak to them that much.'

Because her sister was an in-patient in the hospital, and out-of-area, she also lost access to her day services, which would have been her only social outlet apart from family.

Maria also describes her daughter as being in a ward with older people with dementia, and how little time the nursing staff were able to give to her daughter, necessitating both herself and her husband rotating a shift in the hospital to provide her care needs:

> 'She can't turn on a television she wouldn't know how to operate it … she can't use a phone, she can't talk – she would have been just sitting there and nobody to give her a bit of exercise and bit of time … the nurses hadn't got the time … they were doing their jobs and that is a horrendous hard job and I appreciate them so much. I'd never give out about them … but there was nobody going to go up there and take her out of the bed and take her around for a walk, bring her out – they had their job to do.' [Maria, Mother aged late-60s].

Personal factors: psychological health and homelessness

The issue of psychological health, and the deterioration in the psychological health of carers, in the midst of episodes of homelessness was a thread running through all of the participants (n=5) dialogue. In some instances, they talked of stress, panic attacks and anxiety (n=4) as well as depression (n=3) while two (n=2) experienced suicidal ideation.

Helen talked of her father's illness:

> 'We were in and out of A&E with him – four or five times maybe with what he thought were heart problems, but it was simply down to … stress and anxiety and panic attacks.'

Maria found that the prolonged stress of caring for her daughter in hospital led to a deterioration of her physical health leading to depression and the need to seek medical help. She was sleeping in the hospital at night with her daughter to provide care, while her husband took over during the daytime:

> 'Yeah I was on the anti-depressant. I was going up to my daughter and I wasn't well. I was on antibiotics all the time and I was living in a hospital every day with sick people. You know. So I went downhill, it was just dreadful and I did go on anti-depressants. But I would normally be a bit of a fighter I wouldn't normally be on any kind of medication for depression or anything like that. But I went on

> it because I had to go on it. It was either that or – I could see no end to this black hole that I was in.'

She also talked of how this level of continued care exacerbated her husband's already fragile mental health:

> 'He suffers with very bad depression … he threatened a lot of times to do terrible things – and I went through terrible stress with that. He threatened to commit suicide and what he didn't threaten, and we were all terrible upset over that but, thank God, he didn't.' [Maria, Mother, aged late-60s].

Abeke, on the birth of her third child who had ID and attendant physical disability felt she was close to a 'nervous breakdown.' The maternity hospital kept her as in-patient for three weeks until they felt she could cope back at the Hub.

Aleeki found himself very stressed and said that his wife 'just cried all the time'.

Nadia said that for the first time, she understood how people could very easily become suicidal:

> 'I lost self-esteem. I was always anxious. There was lack of sleep. I did not know how to protect my children. Everything about my life changed. I was just losing it. You start to realise that being suicidal is very easy. Because you think that it's the best thing to do is to just end it.' [Nadia, Mother aged late-40s].

5.2.3 Challenges to housing stability – structural, personal and social factors

Structural factors: lack of support

In the absence of stable family supports, these families depend heavily on the supports provided by the state where they can be accessed.

Not being heard – either through lack of understanding or poor communication – was a thread that ran through most (n=4) of their dialogue when discussing statutory intervention:

> 'The communication from the [statutory agency] was just nil. And you were just like – sitting there waiting, waiting. Every day you were waiting. We were hearing nothing. The days was endless. Waiting. In a hospital. With no care from anybody.
>
> 'We got about three phone calls in a year from her. She'd be making promises and saying [her daughter is] a priority she's – definitely our priority and all that and then you'd get a little bit of hope and then the next thing you wouldn't hear anything and you'd get no answer. That was very depressing and very hard because there was no one coming up front and communicating with you.' [Maria, Mother, aged late-60s].

For Helen, following her sister's hospitalisation, the acute Hospital in which she was staying was not happy to release her back into the care of her father. This necessitated liaising with a Statutory Agency to find a residential place, but she felt they weren't listening to the needs of the family and were also over-riding medical advice:

> 'That's one of the problems that we had in terms of finding a residential place what we thought was suitable for her and what the (Statutory Agency) decided they would give us.
>
> We had a meeting with them in relation to the kind of care that [she] needed and we explained that we wanted residential care for her – they tried to put us under pressure to take … a package that someone would just be coming in and out of the house but long term that wasn't going to work because you know if my Dad got sick again, we'd have no respite – we'd be back to square one.' [Helen, Sister, aged early 40s].

Abeke, talking of her son with ASD, says that she only managed to get him diagnosed as a result of intervention by a family homeless charity:

> 'I had a keyworker there that I have a lady she's from (Family Homeless Charity) and she was the one that helped that pushed through with the early intervention with the diagnosis and everything yeah eventually we got a diagnosis.'

Since being housed, she has struggled to find a school place for him:

> 'We've put his name down for [special needs school]. That he will be linked in for another two years – there's not any other services – I need the support for him.'

Aleeki felt that he and his family were just a number to the Local Authority Housing Agency:

> 'The [Local Authority] they just tell you [that] you have to wait and which number you are they just tell you so you have to wait because we don't know when we will have the house for you. So you have to keep waiting until the time was ready.'

Structural factors: control, choice and coercion

This level of dependence on statutory supports can make families feel like they have limited choice and control over situations when looking for or a suitable place to stay for their family member.

In discussions with a Statutory Agency, Helen says that she felt they were being put under undue pressure to take her sister home:

> ‘[They] said that if we didn’t take her after a period of time we might have to pay for her care in (Community Care Unit) and I was quite taken aback by that.’

Failing to agree to that, they then suggested a nursing home:

> ‘They tried to convince us to place her in a nursing home facility … it looked lovely and all the rest of it nice facility if you were 65 or older. [Helen’s sister is 44]. They really, really put us under pressure… they were saying to us “Well ok you know there are people out there who are elderly who have Alzheimer’s or that kind of thing but there are also patients out there who are under 65…” but the patients who are under 65 who are in the facility have an Acquired Brain Injury so … it just wasn’t appropriate it wasn’t suitable for her.’ [Helen, Sister, aged early 40s].

They were offered, and accepted, a residential place which is outside of their catchment area which means that their father will be unable to visit unless one of his other children take him. They were offered this and asked to accept on the same day.

In relation to private rented accommodation, in all three instances a homeless charity had advocated for more time, or offered to pay additional rent to enable the family to stay in their current accommodation, but this was rejected by the landlords who stated that they wished to sell. In one instance, the landlord started doing up the property while the family were still living there, leading to huge disruption in family life:

> ‘Not only the routine the smell of the paint… just men were working in the house, not caring about us or things – our things were just thrown anyhow but you know what do you do, it’s not your home? [Nadia, Mother aged late-40s].

When Nadia failed to find a home the landlord physically evicted them:

> ‘Yeah – even the day when we went – they were just throwing things away like – “get out, get out” …just making a point that you have to leave today.’ [Nadia, Mother, aged late-40s].

There is also a sense of housing being contingent on ‘good behaviour’ as outlined by Maria:

> ‘I think the only reason why we got this place was the [Disability Agency] knew [her daughter] was going there from the time she was born so they knew our case. They knew as a family that we were never any trouble to them all the years that [daughter] was been over. We never ever caused any trouble we never complained so they knew the kind of family we were.’

Nadia also felt that she got her house because the Local Authority saw that she was a ‘good tenant’:

> 'The lady from the council who had – she came into my house and she had say to me that they had seen my file because there was a meeting … and she said they were pleased because I was having a special needs child I had been a good tenant and I was also studying so they decided that they would help me.'

Personal factors: practical issues

In the period of time between leaving their family or private rented home, the participants and their families moved between three and five times before finding a suitable home over a period of ten months to three and a half years, with an average of 3.8 times for the families or individuals.

This constant change in housing created problems in change of routine for individuals with ID and/or ASD as well as their families:

> 'Settling her into a new home and a new day service and all that will – be a challenge and it will be an upset for her moving.' [Helen, Sister, aged early-40s].

All the participants talk of the amount of time needed for their family member with ID and/or ASD to adjust.

Two adult children with ID and/or ASD moved from the family home to medical facilities. One of the families moved from their private rented flat to a hotel, then a family hub, a flat (which was unsuitable due to a lack of wheelchair access) until an appropriate home was found for them. This took place over three and a half years.

While their initial difficulties arose because of a notice to quit or because of a medical crisis in the case of Helen and Maria, they continued to have problems finding housing solutions that would both keep them close to the services they needed for their family member and provide enough space to facilitate the needs of their adult child and sibling.

When Nadia was offered a house initially, she refused to take it as it meant that there would be no school nearby that could facilitate her son with ASD.

Personal factors: behavioural issues

More than half (n=3) of the participants discussed the effect of behavioural issues on attaining housing.

In the case of Helen's sister, it was her ID, coupled with a severe mental health issue that forced her 81year-old father to look for residential care:

> 'He found it quite stressful – he would be out with her, worrying whether she would behave, and whether he would be able to control her behaviour or manage her if she … got out of hand.'

Abeke and Nadia talked of the difficulty of managing the behaviour of their sons, who both have ASD, and the effect it had on other people in their shared accommodation:

> 'When he was just in one room with me with my [other children] … he was just lashing out [at his siblings] he was lashing out at me everything was just like … everything was upside down it was just – it wasn't ok.' [Abeke, Mother aged late 20s].

Nadia talks of the effort involved in trying to manage in her friend's house:

> 'I could not even stay with my friend's house in the day because I was afraid of what my son was doing. So I have to stay outside all the day every day until evening when we come to sleep and I sneak in – we don't make noise. Unfortunately, we still have to make noise anyway because this boy is uncontrollable.'

Personal factors: changing needs

The constant changing needs of family members with ID/ASD leads to difficulty in people being able to stay in a home unless there is considerable support in terms of change and physical adaptations.

For the two adult family members, their reduced mobility as a result of physical accidents, coupled with the increased ages of their parents, led to the need for an environment more suited to their needs:

> 'I have no downstairs toilet I have only an upstairs. I have only a small home with no – no way of putting a bed downstairs [for her]. [The hospital] wanted me to take her home with a 15 hour a week care package.' [HSE Home Support Service].

Maria explains she and her husband could not have managed, even with the care package:

> 'I think it gets worse as you get older because the person you're minding is getting older – their needs become greater and their needs change. You're getting older you've changed. You're not able to cope as well maybe you might get different ailments and you have to keep going whether you're well or not. You have to be there … whether you're well or not, whether you feel like it – you can't be depressed. You can't be sick.' [Maria, Mother, aged late-60s].

When Abeke first started looking for a larger place to stay, they were unaware that their eldest child had ASD. They only got a diagnosis when his behaviour started to deteriorate in the Family Hub:

> 'I wasn't noticing anything I wasn't – I don't have any clue about what Autism is because there's nothing like Autism aware [in my birth country]. So I don't have any clue it was the … they decided that they had a concern about him.' [Abeke, Mother, aged early-20s].

Subsequently, Abeke became pregnant with her third child, who was born with a significant congenital Intellectual Disability with attendant physical disability.

When Aleeki first became homeless, he and his family were living in a hotel, their daughter was still quite young, and the hotel had a lift. By the time they were assigned their first HAP flat, their daughter was older, heavier but still completely unable to move independently. The location of this flat was good for the family in many ways, but he experienced increased difficulty managing access to the duplex which has a large number of steps up their front doorway:

> 'Yeah it was hard like just to bring [her] up, up, up. You know and then you have to take [the] wheelchair or something like that – it was very tough.' [Aleeki, Father, aged mid-40s].

The family stayed there for 18 months and while they are now housed in a more permanent home, there are still stairs, albeit internally.

Social factors: marginalisation
Lack of support and acceptance, leading to marginalisation, was an issue that the majority (n=4) talked about in relation to themselves and their family member.

For Helen and Maria, there were concerns that a move would make their sister and daughter more isolated:

> 'She won't be going back to that day service she is unlikely to see her friends again … so she's in effect she has lost touch with her friends now.' [Helen, Sister, aged early-40s]

This was important to Maria when finding a place for her daughter who is in her early 30s:

> 'Now had she not got a place in this area and gone somewhere totally out of her catchment area she wouldn't have known anyone she would have been very lonely. I may not have been able to get to her as often. She can't talk. So you wouldn't be able to make a phone call to her because she doesn't speak back she just uses sounds and you know. She would have been heartbroken.' [Maria, Mother, aged late-60s].

The three families who are new to Ireland have no family supports. In some instances, their families were deceased or had been killed and they have no contact with them at all:

> 'We are all over the world – so we don't know [where] each other [in birth country] I was there with my young brother and then we disappear each other we didn't see – since that time you know. Because my Dad and my Mum is passed away a long time ago since we were young.' [Aleeki, Father aged mid-40s].

> 'Yes, I have a lot of sorrow in the beginning before I even left my parents were also killed you know both my Mum and my Dad during the war.' [Nadia, Mother, aged late-40s].

They found that there was a lack of understanding of their children's needs which led to their isolation as Abeke explained:

> 'Yeah – a lot of people you know in somewhere like … some people they just don't understand – you know somewhere like that some people just don't care.'

This caused a lot of problems in the Family Hub and she says she felt very isolated. Even now, attending a recent appointment with her son while pregnant, she felt the doctor was not very understanding:

> 'The last time I went to the hospital for my check-up – he [son with ASD] wasn't really coping – the doctor was like "Don't you have anybody to mind them at home?".' [Abeke, Mother, aged late-20s].

Nadia talked of how she felt trying to manage in one room and trying to give her friend (who had four children of her own) some space:

> 'I find that people are looking through me and saying "what a fool" you know you feel like that…and it may not be the case but it's a mental state that you are in.' [Nadia, Mother, aged late-40s].

For families that have strong social and familial connections in Ireland, they also find themselves without much support outside of immediate family.

For Helen, sourcing and advocating for her sister is a role taken on by herself and her sister only, with little input from other siblings.

Maria who (with her husband) looked after her daughter around the clock in the hospital, says that she has never depended on extended family anyway and that while she was in the hospital with her daughter, she lost close friends:

> 'People that were coming up in the beginning in the hospital didn't want to come up anymore because we were there too long. You lost … a good few friends due to that too. You know people didn't want to know.' [Maria, Mother, aged late-60s].

5.2.4 Home – a safe space and a basic human need

It is clear from the interviews that the individual needs of their child (whether young or adult) defines what a home is for them as a family, and all of the participants (n=5) talked about home being a safe space.

For Helen and Maria, with adult family members it is about being safe, being cared for and having good social interaction with people of their own age:

> 'I'm hoping that it gives her … independence … her own life … that she'll make friends that she'll go to the day service and we'll be able to … have her at home

> for weekends and that if we want to take her away on holidays and that – just that [she has] some kind of a life of her own.' [Helen, Sister aged early-40s].

Aleeki enjoys their home because it is safe and they all have space to interact, have normal family routines and gives them independence:

> 'If you have a home [it] means everything like – for the kids – they have big space. They play like you know so is good. Or sometime they are in one room sometime they are in the sitting room also in the kitchen.'

For Nadia, having a house is the most basic human need:

> 'If you do not have a house you do not have anything. But any human being who is taken out of their house it is like you are stripped bare naked. Everything is taken away from you. You feel the value of life is taken away from you. You feel even your heartbeat is taken away from you. You just become like a nobody. That's how I can describe it. You feel like you don't belong at all. You are stripped from the inside out the day you are taken out of your house and thrown out. You become another human being. Not the same human being. You can take away the money from me take away all the things that I have but leave me in the house. Yes.' [Nadia, Mother aged late-40s].

For Abeke, it means having the space to allow their children to thrive. Her son with ASD is calmer:

> 'He can run around and… we have stimulation for his sensory needs - he has the space to run around.'

Her other child, with congenital ID, is also making progress:

> 'He is trying to take his steps now and, when I went to his physio the last time, they told me things to be doing and I can see huge changes because I can do the things with him here.'

5.2.5 Potential solutions

In as much as the definition of a home is driven by individualised needs, the strategies that the families would like to see going forward are equally diverse, but focus on structural, personal and social issues.

Planning

For Helen, it is the need for continuity of care:

> 'Something needs to be done with the follow-on services. I mean you hear every day of the week that A&E is awash with people … but why are there no beds available? Because people like my sister, like other elderly patients who are waiting on follow on care or nursing home care are in these beds and they can't be moved so it's just…like – a big vicious circle that needs to be tackled in some way.' [Helen, Sister, aged early-40s].

Lack of planning was also referred to by Nadia:

> 'I was thinking for example people who are having special needs like me, if I had already informed the council that I was going to be homeless and I had given them a date – especially with this child - I think there should be some kind of help even if not a whole house where they know is for special needs people so that if you are going to have your own room in an area for special needs people you know that they understand me and that I understand them.'

Maria talks of the sense of loss of placing her daughter in residential care and would prefer to see this process being done over a long period of time:

> 'It's like a bereavement. And it's something you have to go through, and you have to let go. And I think ideally if there was residential places where you can gradually put your son or daughter in when they're well, when you're young and well gradually get them used to it and get you used to it – your change of life, because it is a change of life for you too. All of a sudden – you had no time to do nothing, you had no time to be sick and then all of a sudden you have that bit of good time and maybe you're too old to maybe even enjoy it.'

Social issues
The unsuitability of such housing, and the lack of understanding by other residents was also referred to by Nadia and she would like to see different arrangements for families with special needs children where they could be housed temporarily together:

> 'Other people. I don't blame them. They don't understand the experience so they will judge you and they will make you go crazy. But if there was a special house … it may not be a full house … but it would be a place that is affordable. But to just put us in a house like that [Family Hub]. It's impossible. We can't go to the park because your child is already very aggressive. So, imagine just being homeless means I can't go to the park, I can't go to the swimming pool I can't go to all areas that are families because I'm afraid of my son's behaviour. Now I'm homeless where should I go? Where should I go and hide?' [Nadia, Mother, aged late-40s].

5.3 Individual service user findings

The following is an analysis of the findings of the four individual Service Users who participated in this study. The sociodemographic findings on this participant group is contained in the Participant Profiles (See Section 3. 3 Table 3.2). 5.3.1 Inadequate housing, homelessness risk and return to congregated settings – structural and personal factors

5.3.1 Structural: dependence on private rented market

Of the four participants, two had experienced homelessness as a direct result of being given notice to quit by their landlord. In both instances, they had been living independently, with support, one for five years and one for a year.

5.3.2 Personal: care crisis

Two of the participants had entered care as a result of a care crisis. One was aged10 years and had been in care for 50 years, while the other had come into care at the age of 20 and had been in care for 21 years.

A further two participants had come into care because of parental illness. Of these, one had come into care at the age of 15 and the other at the age of 58 years.

5.3.3 Personal: emergency accommodation

While all (n=4) of the participants had experience of temporary respite housing during their lifetimes, one Service User (where there was parental death) had lived in respite housing for 11 months. Under the classification guiding this study, this is classed as a period of homelessness.

5.3.4 Personal: psychological health and homelessness

All (n=4) of the participants experienced mental health issues, ranging from anxiety and stress to depression due to their homelessness.

Julie, who had been living independently for five years said she felt quite depressed when she realised how difficult it was going to be to source a new apartment. She had been used to security and dealing with homelessness was a totally new experience for her:

> 'I was anxious I was thinking to myself "Oh I hope I get this. I wonder will I get this".'

She explained that she felt 'quite depressed' about it and found it especially difficult to declare herself homeless to her Local Authority:

> 'And then I had to go to the council when I had to go up to the desk to say I was homeless I didn't like that either. I was embarrassed – to having to say that.' [Julie, mid-40s].

Miriam, who is now back in a congregated setting (albeit living in a self-contained flat there) having lived independently for over a year, says that she finds it very depressing:

> 'I can see the ambulance and all coming in here and… hearses and all coming in here where a lot of people dies and all in here. They're old. They're all old people in here.' [Miriam, aged early60s].

Graham, who has shared a bedroom in a Community Residential House for over twenty years, is now finding it an impossible situation:

> 'Just sometimes I get a bit depressed with it and sometimes I get a bit moody with it you know. Some days I'm good with it and some days it's unbearable do you know. [I feel this] tiredness and not wanting to do anything you know like just wanting to get some sleep and stuff you know.' [Graham, aged early-40s].

Aisling, who spent nearly a year in respite sharing a room with another resident, said she wasn't depressed, but she wasn't very happy either:

> '[The woman I shared with] banged doors and wall and all and everything. I wasn't depressed, no, I was just not very happy.' [Aisling, late-50s].

5.3.5 Challenges to housing stability – structural, personal and social factors

Structural factors: lack of support

Two of the participants who had to present themselves as homeless to their Local Authority found the experience less than helpful.

Julie (who had originally lived with her Aunt on the death of her parents more than 30 years before) was taken aback to discover that this was one of the choices that the Local Authority put to her:

> '[They told me I could] go back to my Auntie's or go to a [Homeless Hostel]. I didn't want either of them you see. They said I wouldn't be safe in the hostel that they wouldn't recommend it. And [back to Congregated Setting] yeah. I wasn't happy with that.' [Julie, mid-40s].

Miriam found that there was a lot of questions and paperwork:

> 'They asked me a lot of things - they did yeah. But I answered all the questions and all so. There was a lot of forms. [The Social Worker] helped me with that.' [Miriam, early-60s].

Structural factors: choice and control

All (n=4) of the individuals talked about the lack of choice, control and consultation about where and how they would like to live.

Graham says that when he came into care first, he never envisaged that he would be living the way he is:

> 'Well I didn't actually think I was actually coming to a community house. I actually thought I that I was actually getting my own private place like where I was living on my own.'

Graham is in supported employment and also hold down a part time job and is quite independent:

> 'I shouldn't have to live in a house where there's staff because like I don't need staff care like do you know where I'm independent like. I don't need to be in a house where there's staff or other service users. I'm able to go to work on my own, and travel on my own and go to the parents … I'm able to go to the shopping centre on my own.'

Julie talks of finding the lack of consultation frustrating:

> ‘No one ever asked me, and I used to get frustrated and say ‘I’ve a voice too. Just because I have a mild learning disability, I’m able to speak. I have a voice.’ [Julie, mid-40s].

Aisling had, at one stage in Community Residential, her own flat and was quite content there but was asked to move to facilitate another resident:

> ‘[Other resident] wanted to move into it. So I had to do it - do you know what I mean? Yeah I don’t mind anybody asking me you know – but not telling [me].’ [Aisling, early-60s].

Personal factors: number of transitions

From their original home to their current location, the participants had moved between one and eight times over their lifetime. Their residences ranged from Hostels, to Shared Residential Community Houses, to Respite, an independent flat on the campus of a Congregated Setting as well as Private Rented (own apartment) and House Share (private rented).

Personal factors: behavioural issues

In some instances, participants found the experience of living with other people (often a large number) untenable.

Julie, who had moved eight times over her lifetime talked of the difficulty of living with other people:

> ‘I was in a few houses. The reason why they kept moving me was because I could never get along and they thought maybe by moving me I’d get better but I didn’t. There was some people that couldn’t do – you know – couldn’t do certain things like – that frustrated me you know.
>
> I felt lonely even though I was with other people. It was very hard [there] because there was the nursing end – there was five girls in each house and four staff in a house.’ [Julie, aged mid-40s].

Graham has shared a bedroom with a man 15 years his senior for over 20 years:

> ‘For the last while there’s been a bit of a kind of a tug and pull where we’re at each other’s necks do you know. I can’t sleep at night because the person is in and out of the bathroom like every half hour at night-time going so it kind of keeps me awake you know.’ [Graham, early-40s].

Social factors: social connections

Being close to family, and part of a community or network of friends, was valued highly by all four participants.

Julie, living in her own flat for five years, found leaving the neighbourhood distressing:

> 'I had to say goodbye to neighbours, but I couldn't cause I knew I'd just burst out crying so I didn't you know.'

Aisling, who is now back on the campus of a Congregated Setting (but does not access supports) says that she is now very far away from her family and she finds that difficult:

> 'I don't live near to my family here no – they live all the way [separate Dublin district].'

5.3.6 What home means

When asked what a home meant to them, three of the four participants talked about the importance of being close to family, having friends but most of all, having independence.

Proximity to services

> 'It's important that I can be beside bus stops – so that be near where I can go and see my family I'd need to be [Day Service] too. And I like the shops. I like shopping.' [Miriam, aged early-60s].

Social networks

Being close to family, and part of a community or network of friends, was valued highly by all four participants.

Aisling, who is now back in a Congregated Setting says that she is now very far away from her family and she finds that difficult:

> 'I don't live near to my family here no – they live all the way [separate Dublin district]. However, she feels quite connected to her local community. I can go to the shops on my own. And we have the chats.'

Independence

Graham, who has been room sharing for 20 years would like greater independence:

> 'It just means – living in a home where I can enjoy life and be happy and stuff do you know – making new friends and doing things to my own lifestyle. Where I could be completely independent.'

He says he would like it if he and his girlfriend could live together:

> 'Well I've asked her if she would like to move in with me and she said she would like to do you know. It's something that both of us want.'

He is aware that he would need some support to do this 'like bills and stuff':

For Aisling, it means having control over how she lives:

> 'I like living independent living on me own, do you know what I mean? Yeah. And not sharing with anybody do you know what I mean? And putting me own

> pictures of me own family and putting them up and all I like doing that. And having my own fish tank … and putting it where I like to put it.’

Julie values the freedom to do her own thing without having to ask permission:

> ‘I like it – because – like at night I can put on my telly and play my music and like when I was in the houses and that I couldn’t do that but when I’m on my own like I can. And I like having my freedom to go in and out.’

6.0 Discussion

This chapter examines the results and findings of the qualitative and quantitative data from the DOCDSS study to answer the research question, which was to explore the experiences of people with a disability experiencing homelessness. Examining the experiences of people with ID and/or ASD, and those who support them, allowed us to understand what brought about their homelessness, risk of homelessness, housing instability and for some a return to congregated settings.

Three themes emerged – structural, personal and social factors – all of which act to drive homelessness or homelessness risk, create situations where housing is unstable and can mean the return of individuals with ID and/or ASD back into congregated settings.

These themes are examined in this chapter and bring together the quantitative and qualitative findings under those headings. Initially, the chapter starts with a review of existing housing and care patterns for this group, as well as looking briefly at de-congregation and homelessness prevalence in both families and individuals based on the study data.

6.1 Housing patterns for people with ID and/or ASD

More than a thousand (n=1,130) Service Users were availing of services from the DOCDSS in the Greater Dublin/Leinster region. A higher percentage were living at home (82.6%) when compared with the NIDD database (69%) (Hourigan, Fanagan and Kelly 2018)

Of that number, 47.8% (n=540) were under 18 years of age and living at home with one (16.9%) or both (75.6%) parents. A lower percentage (34.8%) of those over 18 years were living at home with one parent (12.9%) or both parents (21.9%).

Residential Care accounted for 36.1% of the remaining adults in DOCDSS while 25.4% were living in a Residential Community House. A small percentage were living independently (1.7%) or semi-independently (1.0%) with supports.

These figures support previous findings that the majority of care for individuals with ID and/or ASD is provided by family although in this case not for adults (Braddock et al 2001; Hourigan et al 2018).

Homelessness in Ireland has grown year-on-year with the most recent statistics suggesting that more than ten thousand people were homeless in February of this year. This figure excludes those in squats, refuges, couch surfing and rough sleepers. There has been a sharp increase in the numbers of family homelessness (an increase of 300% since 2014) and it is now estimated that one in three people in emergency accommodation is a child (DHPLG 2020; Focus Ireland 2020). Two of the five family participants in this study had spent a number of years in emergency accommodation (with between 2 and 3 children each), and one family had couch-surfed with three children for a number of months.

Of the households qualifying for social housing in 2019, more than a quarter had been on a housing list for more than seven years (Focus Ireland 2020). In DOCDSS, 45 people (39.5%) of the general homeless category were on the local authority housing list, with 12.3% being on the list for between eight and ten years.

The single largest contribution to family homelessness was as a result of eviction following sale by a landlord of private rented housing (Focus Ireland 2020).

Many such families who present as homeless to their local authority find themselves in temporary accommodation (Hotel, B&B, Family Hub) often for long periods of time, to the detriment of family life and health, giving them little control over their environment (DHPLG 2016; ICON 2019).

There is also evidence of a significantly higher proportion of families who are new to Ireland accessing homelessness services – 33.0% of the homeless population as opposed to 11.6% of the general population. This cohort have been found to have smaller social networks and as such have little in the way of support of family and friends and less knowledge around supports available, leading to an acknowledged lack of equitable support (Dublin Regional Homeless Executive 2018).

Similar figures are borne out by the DOCDSS database, which lists 45 families (31.4%) who are new to Ireland and fall into the category of homeless using the classification guiding this study. However, the national percentage may indeed be higher, as qualitative data indicates that for two of the three family participants, there was no awareness of the ID and/or ASD displayed by their children until intervention by outside agencies while homeless.

As stated earlier, prevalence rates for individuals with ID and/or ASD that are living homeless in Ireland have yet to be identified. There is widespread evidence amongst front line staff working in both the disability and homelessness sectors attesting to the fact that people with ID and/or ASD are experiencing homelessness (Disability Federation of Ireland 2018).

According to the DOCDSS database, three people are recorded as homeless. However, the definition used is in line with the legislative Irish definition of homelessness (Dublin Regional Homeless Executive 2019). Subsequently, work was undertaken by the Social Work team at DOCDSS to review families and individuals that met the classification of homelessness guiding this study (FEANSTA 2014) in the previous ten years. The definition encompasses situations were individuals are in insecure, inappropriate or inadequate housing. This more inclusive definition was applied in order to ensure relevance for the group under discussion, namely those with an ID and/or ASD and their families.

This resulted in 12.8% (n=145) individuals and or families identified as homeless or at risk of homelessness. A number of this group (n=31) were crisis admissions to hospitals or service, but effectively homeless.

Of that number (n=145), individual/family homelessness account for 78.7% (n=114) of all cases, while crisis admissions account for 21.3% (n=31).

6.2 Structural factors around homelessness/risk, housing instability and return to congregated settings

There are a number of structural factors which can lead to homelessness, most notably socioeconomic issues around poverty and lack of social housing, leading to an over-reliance on the private rental market (Focus Ireland 2018). This study finds that people with ID and/or ASD and their families also face additional structural difficulties with inappropriate accommodation as well as a lack of awareness of their needs at a statutory and local authority level.

6.2.1 Socioeconomic, cultural and ethnic issues

In line with findings that people with disabilities have a higher level of reliance on social support (Watson et al 2018; Housing Agency 2020), the current study found that of those presenting as homeless or at risk of homelessness, 42.7% (n=62) of the sample (n=145) reported relying on social welfare.

Families caring for a person with ID and/or ASD are at an increased risk of falling into the poverty trap as a result of the financial and social impact of caring for a family member, and this leads to a number of problems, the most notable of which is homelessness (Chapman et al 2008; Emerson 2007; Emerson et al 2010).

People with disabilities in Ireland are three times more likely to experience poverty with less than one-fifth (17%) in employment and more than half (56.5%) unable to go to school, college or work (Central Statistics Office 2016). Of the four individual Service Users, only one was employed (by the DOCDSS service) and had progressed past primary level equivalent education. Within the families, two had (in the past) one parent working full time, while for those of current working age (n=3) only one had a family member who was employed (part time).

Additionally, research suggests that there is a high level of co-morbidity between ID, ASD and physical disabilities and that this can lead to social vulnerability, unemployment and high levels of need (Cooper et al 2015; Health Research Board 2010; Matthews Bell and Mirfin-Veitch 2018; Owen and McCann 2018; Srivastava and Schwartz 2015; Stone 2018).This is borne out in the homeless sample in this group within DOCDSS, of whom 92.4% have a secondary diagnosis (ASD, mental health, physical disability or other chronic health condition), indicating a higher level of need with a broader range of supports.

6.2.2 Over-reliance on private rental accommodation

This poverty trap leaves families and individuals economically dependent and for these participants, the main structural driver for homelessness was given as an over-reliance on the private rental market for housing. Of the nine participants, five were on the local authority waiting list (having been given notice to quit by their landlord) and could not secure alternative accommodation. This resonates with previous findings that people with disabilities report facing discrimination when trying to rent, and find it difficult to source accessible, affordable accommodation with a landlord who will accept HAP (Watson et al 2018).

Staff Members point out that a lack of security of tenure, from over reliance on the private rental housing market, is the single greatest cause of housing instability. This insecurity coupled with a lack of services leads to families and individuals experiencing recurring homelessness. For Staff, being able to keep individuals and families physically close to services (such as respite, day activation, schools etc) is essential in helping them to manage their or their child's disability. Services are of great importance to families who are new to Ireland, given the absence of family or social networks (Dublin Regional Homeless Executive 2018) and they depend on such services for support, guidance and respite.

Certainly, there is evidence to suggest in their dialogue that families will, where they can, refuse housing where it means moving out of the catchment area for services and that waiting lists for services in other areas can be lengthy, but equally that this is not always understood by the local authority with whom they are interacting.

The lack of availability of suitable, affordable social housing was the primary reason for individuals who had to return to residential services. In this study, two Service Users had been given notice to quit by their landlord and, failing to find alternative accommodation in the private rental market, had returned to residential services for a year or more.

Additionally, a programme aimed specifically at transitioning individual adults out of residential care and into independent accommodation (with supports) saw three of six individuals returning to residential services having spent a number of years living independently because of notice to quit by landlords wishing to sell their properties. And although they were subsequently re-housed, none returned to the private rental market. This finding highlights the difficulty faced by individuals with ID and/or ASD in securing private rented housing that is accessible, affordable and where they are not discriminated against or treated differently because they have difficulty navigating social norms (Watson et al 2018; Lougheed and Farrell 2013).

6.2.3 Sub-standard accommodation and practical difficulties

Staff Members within the DOCDSS were aware of instances where accommodation that had been offered was sub-standard or that it presented practical difficulties – most within the private rental sector but many within local authority housing. They cited incidences where families took accommodation that was clearly unsuitable for fear they would go to the end of the housing list. This reflects concerns in previous research where social control strategies can lead to challenges which negatively impacts accommodation status (Evans 2011; Johnson, Fitzpatrick and Watts 2018; Markee 2009).

This included, but was not limited to, instances where equipment (such as wheelchairs) did not fit past doors, limiting movement within a house or apartment; spaces that were too small to allow for essential equipment to be used to facilitate developmental progress as well as unhealthy (damp) accommodation, overcrowding or lack of outdoor space.

Practical difficulties around navigating a very complex housing system were of concern to the Staff Members supporting Service Users and their families who found themselves spending a lot of time accompanying Service Users to house viewings, as well as interpreting (where required for families new to Ireland) and form filling. They act as facilitator, supporter and advocate in helping families, in particular those new to Ireland, to negotiate the housing system, connecting them with cross-sectoral agencies so that they can advocate for themselves independently. This support is essential, as financial skills and high-level economic concepts can present a challenge and individuals with ID and/or ASD are at higher risk of financial and emotional abuse and neglect in comparison to other homeless individuals (Lougheed and Farrell 2013).

Such difficulties have emerged in previous research where communication difficulties (due to poor literacy skills), socioeconomic disadvantage and difficulty navigating social norms have all been linked to people with ID and/or ASD experiencing inequalities (Burge 2009; Koritsas and Iacono 2007; Lougheed and Farrell 2013; Van den Bos et al 2007).

While there is evidence of some progress being made in this area in the provision of accessible material (NDA 2018b; Health Service Executive 2019) some of the standard bureaucratic requirements (such as household bills in their own name, passport, driving licence) are simply not in the possession of people with ID and/or ASD.

6.2.4 Lack of awareness of needs

From the Staff perspective, it was generally felt that there was a lack of awareness within the housing system and the local authorities of the needs of individuals with ID and/or ASD, especially where there was an attendant physical disability. The link between ID, ASD and physical disability discussed previously leads to vulnerability and acts as a catalyst for homelessness (Cooper et al 2015; Health Research Board 2010; Matthews Bell and Mirfin-Veitch 2018; Owen and McCann 2018; Srivastava and Schwartz 2015; Stone 2018). Staff Members point to instances where parents are thought to be ‘fussy’ in requesting specific accommodation for the needs of their child, especially where there was a diagnosis of ASD. However, these parents’ needs are acknowledged by research which indicates that children with ASD have a range of idiosyncratic needs and require a broad spectrum of modifications in housing (Owen and McCann 2018).

There is evidence, particularly in the findings of the family Service Users, that they feel a distinct lack of support from the statutory agency tasked with the provision of disability services. This finding is reflected in previous research where there is a noted lack of consultation and choice around moves from congregated to community settings (O’Donovan 2016).

This lack of consultation and choice leads to many families and individuals being placed in accommodation that simply does not fit their (or their child's) physical or sensory needs. The high level of transitions noted in this study would suggest that families and individuals move a number of times and that each time their accommodation was partly or wholly unsuitable for their needs at the present time or in the future. Each transition means additional stress for the family and the individuals with ID and/or ASD.

6.3 Personal factors around homelessness/risk, housing instability and return to congregated settings

The personal factors associated with homelessness are cited as those around health issues (addiction, mental health issues) and family and/or relationship breakdown (Focus Ireland 2018). For this cohort, personal factors centre on issues around care crises, psychological ill-health and behavioural issues.

6.3.1 Care crisis and psychological ill health

The personal factors leading to poor housing varied depending on the needs of the individuals who participated in this study.

As stated earlier, according to the DOCDSS database, a higher number of individuals remain at home cared for by family - 82.6% as opposed to 69.0% recorded in the Health Research Board dataset (Hourigan, Fanagan and Kelly 2018). In spite of extensive family lobbying for increased community services to support families to continue to provide such care at home, the bulk of care nonetheless falls on mothers (Patton et al 2018; Wang 2012). Certainly, for all the Service Users (n=9) who participated, they had been cared for in the past, or were being actively cared for at the time of the research, by their mothers.

This level of care can lead to high levels of parent related stress which can lead to poorer mental health (anxiety and/or depression) and they are much more likely to experience poverty and social exclusion than the general population (Burton-Smith et al 2009; Emerson and Brigham 2015; Hubert 2011; Johnson et al 2018). However, research indicates that investment in respite care has the lowest spend (at 2% of the total budget) of the national budget for disability services, even though it is viewed as a critical factor in supporting families to continue to care at home (NDA 2018a). A recent report (reported in the Irish Times) notes that lack of a long-term investment approach to disability funding by the HSE has led to 'phenomenal growth' in high-cost emergency residential placements for people with complex needs (Irish Times 2020). Investment in averting a care crisis may be important in the prevention of homelessness for this cohort.

Across all three groups of participants, the issue of care crisis emerged. Staff Members point to numerous instances where a care crisis had occurred. In some instances this had been due to assaults on carers (12.9%) the increased care needs of the person with ID and/or ASD (3.2%), a decrease in ability to care (25.8%) (due to age, physical or mental health needs) or simply an inability to continue to cope with the demands of care (45.2%). This would indicate that in 71.0% of crisis admissions, the main factor is that the carer is unable to continue with the demands of caring, or experiences ill heath themselves. This is borne out by research indicating that there is little or no planning for the future care needs of people with ID and/or ASD which will occur as traditional caregiving patterns (i.e. family) decline and caregivers age (Brennan, Murphy, McCallion, McCarron 2017; Inclusion Ireland 2019).

Two of the family Service Users who took part in this study were in placements in medical settings (Acute Hospital) due to sudden reductions in mobility. This reduced mobility, along with ageing carers and unsuitable housing (no downstairs bedroom/toilet facilities) meant that the individuals could not return home and a placement had to be found for them, although in both instances they remained in these acute medical settings for over a year.

Of the four individual Service Users, two had come into services suddenly as a result of parental death and a further two had come into services as a result of a care crisis at home.

Staff Members also point to instances where families with younger children who have high levels of need find they simply can no longer cope due to lack of support and this can require crisis admission. However, the number of care placements for such children for the Dublin area is low (at 3 full time residential placements).

While anxiety and depression has been linked with the burden of care for family members (Burton-Smith et al 2009; Emerson and Brigham 2015; Hubert 2011; Johnson et al 2018), there is limited research into the direct impact of poverty, homelessness and the mental health experience of people with ID and/or ASD and their families (Emerson and Parish 2010).However, all participants in this study talked of the effect of caring, coupled with the added difficulty of homelessness, on their psychological health.

For family Service Users living in emergency accommodation (or couch surfing), the situation brought on depression and anxiety in all five instances, and in two instances suicidal ideation. For individual service users, three of the four said that they experienced stress, anxiety and depression as a result of their homelessness.

6.3.2 Emergency accommodation and regression in children

In instances where there is not a care crisis, the qualitative findings indicate that families and individuals who present as homeless did so as a result of a notice to quit by their landlord, and were unable to secure new tenancies due to refusal by landlords to accept HAP tenants or high rents (out of reach of the participants) in line with findings in this area (Simon Community 2020).

Five of the nine Service User participants found themselves in this position. In presenting to their local authority as homeless, and in the absence of available housing, one individual was offered hostel accommodation (and also advised against it) and three families were referred into emergency accommodation. One mother refused and opted to couch-surf with her three sons.

Emergency accommodation in Ireland takes several forms - Hostels (mostly for individuals, B&Bs or Hotels (for families and individuals), and Family Hubs (Focus Ireland 2020). Staff describe these types of accommodation as ‘horrific’ and point to issues that affect the family (such as loss of normal family routine) as well as regression and behavioural changes in children. Providing services to families, who are often in one room, makes privacy impossible leading to a reduction in the ability to provide support to families. Staff Members also point to unacceptable levels of overcrowding and noise.

This is acknowledged by the Department responsible for housing in Ireland which finds that even a short length of time in emergency accommodation has a detrimental effect on family life (DHPLG 2016). These findings were borne out by the family Service User participants, who pointed out that they could not cook for their family, had to eat in their bedroom and share washing and fridge facilities with a large number of other families.

In the two instances where the child had ASD they found that the behaviour of their child had become unmanageable as a result, leading to further stress and isolation. This finding reflects research which points to a significant increase in ‘conduct difficulties’ in children with ID and/or ASD who are exposed to negative environmental factors, such as poorly maintained housing (Emerson et al 2014).

6.3.3 Behavioural issues

There is a high level of non-diagnosis and therefore limited support for people with Autism throughout their life course (Leedham 2002; Simons 200; Talbot and Riley 2007). For families who are renting, and who have a child with ID and/or ASD, they may find that there is poor understanding of their child’s limitations. These children can present with a greater degree of hyperactivity, distractibility and impulsivity (Matthews, Bell and Mirfin-Veitch 2018) often leading to property damage. Staff point out that in many instances landlords are under pressure to move such families as a result of noise complaints by neighbours or refuse to return deposits (as a result of property damage) leading to further financial hardship.

Individual Service Users report difficulty with other residents in shared Community Residential Housing or while in respite care. In both instances, houses can be shared by four or five individuals with attendant care staff (which can number 4) leading to busy and noisy households, which some of the individual participants found unbearable. The individual Service Users who participated had mild levels of ID and/or ASD. They report finding the behaviour and limitations of other residents in such settings (who may have had moderate or severe ID and/or ASD) frustrating, disruptive and disturbing.

Family participants in this study point to the difficulty of navigating their child’s behavioural difference in emergency accommodation settings.

6.4 Social factors around homelessness/risk, housing instability and return to congregated settings

While structural and personal factors play a role in housing instability for people and their families with ID and/or ASD, social factors, especially around social connectedness, stigma and social exclusion, also play a crucial role.

6.4.1 Social exclusion, social capital and stigma

As noted in the previous section, there is often little understanding of the needs of individuals and families with ID and/or ASD. Having an intellectual disability remains a powerful social identity with 'fear of difference' acting as a barrier to engagement with the wider community (Anderson and Bigby 2016; Beart, Hardy and Buchan 2005; Scior and Warner 2016). This stigma, as a mark of 'social disgrace' allows for members of society to discredit individuals based on their 'difference' (Corrigan 2004; Coorigan Roe and Tsang 2011).

Certainly, the experiences of the family Service Users in this study indicates that this stigma was either overt or personally felt by the families in relation to their children while in emergency accommodation. Staff Members also find that that individual Service Users may have communication difficulties or be unable to conduct themselves in a way that society finds acceptable, leading to loneliness, poor understanding, ostracism and as a result at a high risk of abuse.

This stigma can go beyond the individual with ID and/or ASD, to families leading to social withdrawal and subsequent health problems (Ali, Hassitosis, Strydom and King 2012; Mitter Ali and Scior 2019).

The family Service User participants in this study report limited social and family networks. While this may be understandable in the instances where the families are new to Ireland (n=3) nonetheless, other families report having little or no family support and friendships falling away over a period of time (especially in crisis).

Where individual participants have been living in an area for a period of time, with consistent supports, there is evidence that they feel part of their community and connected to neighbours. However, for all the individual participants, the need to stay close to family was of paramount importance, signifying that family forms an enduring social bond.

Family ties, as an essential part of social capital, has a focus on 'high-density' relationships where individuals have a number of interconnected people within their network to support them, and has positive health consequences (Coleman 1988; Baker 1984; Widmer, Kellerhals and Levy 2004; Widmer, Chevalier and Dumas 2006).

Individuals living independently or with family are more likely to have friends outside of a care structure (McCausland et al 2017) and those living with family had stronger social networks than those living in residential care (Krauss and Erickson 1988; Krauss Seltzer and Goodman 1992).

Staff in this study indicated the importance of being able to maintain such relationships independently, and cited instances where Service Users were too far away from public transport and experienced pervasive loneliness as a result.

6.4.2 Marginalisation

A Staff Member tasked with locating individuals into independent living reports that they often face alienation from their community, and that their obvious social difficulty means that they may experience difficulties being accepted as part of their new community. Similar findings in research suggest that cognitive and functional impairments lead to communication difficulties and social discrimination and that navigating social norms can compound these stressors (Burge 2009; Lougheed and Farrell 2013).

6.4.3 Lack of individualised support

While there is evidence of policy commitment to individualised support in housing in transitioning people from residential centres this is not backed up by funding increases - disability services nationally saw funding reductions of 7% over a period of time when the demand for disability services grew by 8.4% (NDA 2018a). More recently, a report for the HSE (reported in the Irish Times) finds there was a funding gap of €78.5m in 2019 alone for disability services (Irish Times 2020).

Policy around moving individuals from Congregated Settings to community residential is seen to be significantly under resourced by Staff Members. DOCDSS database statistics indicate that there were only a small number of transitions in the period 2016 to 2018 (n=13) and none for 2019 and at time of writing in 2020. By 2019, the number of people remaining in congregated settings was 1,953 (HSE 2020). However, DOCDSS had initiated de-congregation as early as 1991 with the establishment of several purpose-built bungalows to accommodate Service Users. These figures are not counted in the HSE data set as they are on a campus and not in a community setting. The model proposed initially in 2011 envisaged new models of accommodation and help to live in the community in the form of dispersed housing with individualised supports (Health Service Executive 2011).

The most recent progress report on the de-congregation indicated that for the majority of Service Users (64.0%) a move to the community would mean high or intensive levels of support. And while moves to the community can improve the quality of life of individuals (Lombard 2019) it can lead to an increased risk of homelessness resulting from insufficient supports (Backer, Howard and Moran 2007; Burns 2003).

6.5 What is home?

Under UNCRPD, home should about the equal right of all people with disabilities to live in the community with the same rights as others (United Nations 2009). However, the right to housing as a core human rights concept is absent from Irish housing and health policy in the population of people with ID and/or ASD (O'Donovan 2018). The social issues around homelessness and housing are the factors that emerged most frequently with the majority of the Service Users (who had family and friends in Ireland) when discussing what home meant to them, with proximity to family and friends of most importance.

Access to the potential for social interaction also featured, with a majority of individual Service Users stating that they liked being able to go shopping, visit friends and attend their day activation.

Independence featured with all the Service Users discourse – being able to be an independent actor in one's own life was crucial to them. This meant anything from being able to decorate their home the way they wished to not having to ask for permission to have friends in or to go out.

For families with children with ID and/or ASD independence meant that they could cook their own food, eat at their own table and ensure that their children could interact as they wished under their own roof, enabling them to establish clear routines that helped developmental progress.

For those with adult relatives now living in residential care, home meant a place where their adult child or sibling could interact with their peers while still maintaining family relationships.

All the Service Users in this study stated that having a home meant having a safe space.

6.6 Potential solutions

Participants were asked what they felt was needed to address the issue of the experience of homelessness in people with a disability.

Staff and family Service Users pointed to a lack of planning and the need for a National Policy on Housing – especially in the absence of policy around housing for young and adult children with an intellectual disability.

They also felt there was a need for an improved knowledge base amongst housing providers and local authorities around the needs of individuals and children, especially those with ASD.

Family Service users suggested that there should be a greater degree of planning for future care needs, and that this should involve consultation with families and timely communication with statutory agencies. More understanding across both agencies and communities was also called for.

Individual Service Users wanted greater involvement and consultation around their housing needs.

7.0 Conclusion and recommendations

7.1 Study Limitations

Before looking at the conclusion and recommendations of this study, it is worth first noting the limitations of the study.

7.1.1 Sample size

As explained earlier (Section 2.1a(i)) the sample size is of necessity small but allowed for a concise case study approach (Flyvbjerg 2011; Stake 2005; Yin 2012). The use of a qualitative Grounded Theory approach allowed for the participants to fully explore their ideas of home, and the barriers they faced to achieving that aim, either for themselves or for a family member. Due to its small sample size and the fact that it used data from one Service Provider in the Dublin area, it cannot be said to be generalisable at a national level.

7.1.2 The use of gatekeepers

There is concern over the use of Gatekeepers for any research study, and most especially with vulnerable groups, particularly where the access is provided by the Gatekeeper who provides a service to the participant. This concern is related to the potential for social control (Broadhead and Rist 1976). However, every effort was made to constantly assure participants that their access to services would not be impacted by their decision whether to participate or withdraw at any time.

7.1.3 The COVID-19 Pandemic

Initial approaches to potential participants had been made by the on-site Co-ordinators in early March following the granting of Ethical Approval. By mid-March the Irish Government had announced a swathe of restrictions to reduce the spread of COVID-19. This included the closure of care homes, schools, businesses, a cessation of all non-essential travel and keeping to within a two-kilometre limit of home. [See Appendix 2].

Following advice from the Scientific Advisory Committee (22.04.2020) attached to this study, it was decided that the individual Service Users who wished to participate should be facilitated to do so by phone, noting that there was concern about the viability of this approach in terms of their interaction with a person not known to them. It was agreed that the Research Assistant (RA) would phone in advance (following provisional agreement by the participants) to establish a rapport and then arrange for time of interview, if this was still agreeable to the potential participants. Seven of the participants, after an initial ‘getting-to-know-you chat’ expressed a desire to complete the interview at the time of the first phone call. Two individual participants elected to have a ‘What’s App’ getting-to-know-you chat, followed by phone interview.

While there was initial concern that there may be a loss of information (due to difficulties in communication, inability to read facial expression, body language etc) as a result of using the phone only, it is impossible to know if this was the case.

Certainly the Research Team felt that the interviews had provided more than sufficient information to provide a basis for thorough analysis.

The use of this method of interview meant that only people with a mild/moderate ID and/or ASD were approached for interview and the study does not include the voice of those with a more severe disability.

7.2 Conclusion

People with a disability emerge as one of the most disadvantaged groups and are over-represented in the homeless population. More than one-in-four homeless people in Ireland have a disability and they experience high risks of discrimination, environmental and housing deprivation (Grotti, Russel, Fahey and Maitre 2018). Within that group, global cognitive impairments are more prevalent in the homeless population, and people with an ID and/or ASD are more likely to experience homelessness and housing discrimination (Brenner et al 2017; Watson et al 2018; Mercier and Picard 2011).

In the absence of sufficient social housing, reliance on the private rental market in its current form is not feasible, especially for a group already facing poverty, economic dependence and social marginalisation.

Emergency accommodation, in its present form, is not suitable or appropriate for most families, but is especially challenging for families who have a child with ID and/or ASD with a possible attendant physical disability. Placement of a family in one room with limited facilities has led, in this study, to severe psychological difficulties in carers and behavioural and development regression in children.

Using the classification of homelessness guiding this study (FEANSTA 2014) families find themselves, even in non-emergency accommodation, in inappropriate housing. The use of this definition (as opposed to less inclusive legislative Irish one) meant that the study has particular relevance for this cohort. Examples in this study include those who have limited space, which restricts movement; lack of outside space (essential for children with ID and/or ASD); in houses where bedrooms and bathrooms are upstairs where there is a child with ID and/or ASD and attendant physical disability as well as general living conditions which are not conducive to good health (such as damp/fungus on walls). Such examples would be excluded under the Irish definition of homelessness.

These families also experience housing instability brought on by an over-dependence on the private rental market which leaves them open to market forces where they often find that rent costs are out of their reach and that there is an unwillingness for landlords to accept HAP tenants.

Inappropriate and unstable housing is also a factor in this study for older adults with ID and/or ASD living with ageing carers. They do not have the social, cultural and economic resources of their non-disabled peers (due to lower education and employment possibilities) and so find themselves at a distinct disadvantage when trying to navigate the housing market independently.

For adults with ID and/or ASD who are living at home cared for by parents or siblings, there is evidence in this study to suggest that they experience similar issues, with particular difficulty accessing the social housing lists, either because they are not encouraged to do so by their carers or because they are not viewed as a priority on the social housing list.

Inappropriate housing is also experienced by individuals who are placed in acute medical settings, respite or in a return to congregated settings for long periods of time, which in turn leads to psychological distress.

While there is a policy on disability and housing, it focusses on those with a physical disability and those who are ageing. There is no specific policy that meets the needs of children and their families in gaining and attaining suitable and appropriate housing within the ID and/or ASD cohort. National spend on disability services generally has dropped while there has been an increase in the numbers needing support (NDA 2018a).

The DOCDSS as a Support Service employs innovative practices to work in partnership with people with disabilities to empower them to live a more independent life possible, using best practices such as SRV. Their commitment to advance planning in facilitating ageing in place for people with dementia has gained them awards. The recent formal establishment of the Marillac Housing Agency as a separate agency will allow them access to a greater range of cross-sectoral supports in housing for their Service Users. However, all of these innovative practices could be hampered by lack of funding and poor Statutory agency approaches at a national level.

It is clear from this study that there is a greater need for an inter-agency or inter-sectoral approach to the issue of people with disabilities experiencing homelessness. Housing, and lack of housing is a non-medical determinant of health and as such, inequalities in health can be linked to disadvantages in other areas. Responsibility for addressing this issue lies across a number of different Statutory agencies – disability services are under the remit of the Department of Health, housing is the responsibility of DHPLG (as well as a number of local authorities) and Social Inclusion yet another Statutory agency, namely the HSE.

Addressing the structural, social and personal issues requires an inter-sectoral approach. In this way, a life course approach could be implemented which would account for early negative life events (disability, homelessness, lack of access to education, poor supports) which impact greatly on later health outcomes.

There is also a considerable need for communities to become engaged in both supporting, and understanding, the needs of people with ID and/or ASD.

Homelessness is not solved purely by the provision of a roof over someone's head. In order for individuals and families with ID and/or ASD to not only survive, but to thrive, there needs to be an individualised, well-funded person centred care plan that is put in place at an early stage (before a family or individual becomes homeless) and has the capacity to adjust to changing needs over the life course of the individual.

7.2 Recommendations

While the findings of this study are not generalizable due to their small sample size insights were gained into the lived experience of people and families with ID and/or ASD experiencing or being at risk of homelessness. The recommendations draw on ways to improve/prevent these experiences. Many recommendations may also be of benefit to other vulnerable groups in that they call for both a review of existing policy and suggest the implementation of preventive strategies. Based on the quantitative results and qualitative findings, recommendations are presented at an overarching and service level. The first are recommendations specifically for housing policy in Ireland for people with intellectual disability and/or autism, while separately recommendations for the DOCDSS are made.

7.2.1 Overarching recommendations

With regard to Housing Policy in relation to people with ID and/or ASD, it is recommended that:

- That the National Housing Strategy for Persons with Disabilities, which is due to be developed during 2021, has a specific focus on People and Families with ID and/or ASD framed by a life-course and human rights perspective.
    - It should acknowledge that adults with ID and/or ASD living with parents but wishing to live independently need to be facilitated.
    - The policy is adequately resourced
    - We acknowledge that this recommendation, in calling for a policy based on a particular disability type, goes against the mainstreaming of disability services, policies and strategies that is part of government policy and has been advised consistently by the NDA.
- The social worker observations in this study outlined a number of barriers for persons with ID and/or ASD in accessing the housing market. They recommended a review of Social Housing/Private Rental Market is undertaken and focuses on the following issue.
    - Reducing bureaucracy in applications for housing and accessing HAP payment: streamline/simplify access by provision of accessible materials

Specific gaps in education and engagement in the housing sector were identified and as such it is recommended that there is a need for:

- Establishing a forum for cross-sectoral collaboration

- Increasing awareness of the needs of people with ID and/or ASD across Statutory and Housing and Disability Services as well as for landlords operating in the private rental market, through education and incentives (such as financial incentives to provide adaptations)
- Revising income thresholds for eligibility in local authority housing for people with ID and/or ASD and their families
- Providing greater protection from eviction
- Identification of the prevalence of homelessness/risk of homelessness on a national level of people with ID and/or ASD to allow for appropriate responses and future planning
- Engagement of communities, Staff and Service Users in participatory dialogue to promote care in the community

7.2.2 Recommendations for DOCDSS

The DOCDSS provided a useful case study location for exploring the issues of homelessness and risk of homelessness for people with ID and/or ASD and their families in a capital city. While this study is not generalisable to the general population it is likely that other disability services are no doubt encountering similar challenges to supporting this group in obtaining sustainable, safe, secure and appropriate housing and may benefit hugely from the insights provided by DOCDSS and their Service Users in this study. There are also specific recommendations that DOCDSS may wish to consider to support their future planning and development of innovative and person centred supports for their service users.

- To inform and enhance planning the service could
    - Expand the current database review to ensure that information gathered can generate best evidence to highlight need, for example, including age of carer
    - Identify at the earliest stage families and individuals most at risk of homelessness/housing instability, for example, expanding definition of homelessness in line with the European definition and staff observations
    - Continue implementation of the new AHB status (Marilliac Housing Association) as a specific service driven initiative to address the multi-faceted issue of homelessness
- Consultation should continue to inform DOCDSS practice ensuring that
    - Individuals and families continue to be fully engaged in choice around their home
- Information sharing should continue and develop
    - Seek to share information, generate discussion and identify specific strategies with staff, families, service users as well as local

authorities involved in housing and Statutory Agencies responsible for the issues (DHPLG, DOH, HSE, DSP).

7.2.3 Future research

- As this research was conducted during COVID-19 restrictions, it was limited to the experiences of Service Users with mild to moderate ID and/or ASD. Future research should include the voice of those with more profound levels of disability.
- Review income level caps for adaptation grants or follow the Danish model and based on need not income
- Recognising that emergency accommodation is in no way desirable, the current options are even less suitable for people with ID and/or ASD. As such, suitable alternatives to emergency accommodation are required which would allow for earlier intervention with additional financial supports to enable them to stay in their accommodation or quickly find new accommodation. Specific research is needed as to what this could look like and how this would work in practice.
- New and innovative models of housing for people with ID and/or ASD which prioritise independent living options with supports as required and individual choice need to be examined and explored. Some examples of innovative models have been identified in the literature in Denmark, Australia and Canada but further evidence is needed on these models including how they would suit the Irish context
- An advice paper on achieving Universal Design in new housing was presented by the NDA to the Department of Planning, Housing and Local Government and is currently under consideration (NDA 2019). This should be revisited with a view to establishing requirements for Universal Design in new builds

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APPENDIX 1 Definitions

1.1 Intellectual disability

There are several terms that are somewhat interchangeable in describing persons who experience intellectual disability. The classification of such a disability is referred to as 'mental retardation' (World Health Organisation 2018) in some instances and 'intellectual disability' (American Psychiatric Association 2018) in others. Within that spectrum are terms such as mental handicap (now less often used), learning disability (most commonly used in the UK), 'cognitive disability' (used in the US) as well as 'development disorder' and 'global developmental delay' (Gulati et al. 2018). This study uses the term 'intellectual disability' according to the definition of DSM 5 (Diagnostic and Statistical Manual), which bases testing both on standard IQ scores as well as tests for adaptive functioning. People with intellectual disability is the generally accepted term in Ireland and increasingly so internationally. The symptoms of ID begin during childhood or adolescence and most delays in language or motor skills will be evident by the age of two years. However, some milder forms may not be diagnosed until the child attends school. There are a number of co-occurring or related mental health, neurodevelopmental, medical and physical conditions which frequently co-occur with ID, including cerebral palsy, epilepsy, autism/ASD, AHDH (Attention Deficit Hyperactivity Disorder) as well as depression and anxiety (American Psychiatric Association 2018).

1.2 Autism/ASD

Autism Spectrum Disorder (ASD) is defined as 'persistent deficits in social communication and social interaction across multiple contexts' manifested by deficits in social-emotional reciprocity, nonverbal communication and relationships. It can result in stereotyped or repetitive motor movements, insistence on sameness, fixed interests and hyper or hypo-reactivity to sensory input. ID and ASD frequently co-occur. For a diagnosis of Autism/ASD, symptoms must be present in the early developmental stages which may not become marked until social demands exceed limited capacities (American Psychiatric Association 2013).

1.3 FEANSTA classification of homelessness

Homelessness in a European context is classified by the European Typology of Homelessness and Housing Exclusion (ETHOS) developed by FEANSTA (2011). This classification takes account of homelessness as being not just without a roof (i.e. sleeping rough), but also house-lessness (those living in temporary accommodation), insecure housing (staying with friends/family or under threat of eviction) and housing that is inadequate in that it fails to meet the needs of the people living there or is associated with inconveniences (EU 2014).

1.4 Conduct disorder/difficulty

This refers to a group of persistent and repetitive behavioural and emotional difficulties that young people can display because of a number of social, medico and situational reasons (including traumatic life experiences) as well as genetic vulnerability. Such children may have difficulty following rules, displaying empathy and behaving in a manner that is socially acceptable. As a result, they are often viewed as ‘bad’ or ‘delinquent’ as opposed to psychologically unwell (American Psychiatric Association 2020).

APPENDIX 2 COVID-19

2.1 COVID-19 experiences – a qualitative overview

This research study was undertaken during the COVID-19 Pandemic. The first confirmed case of COVID-19 occurred on February 29th. By March 9th mass gatherings were cancelled. On March 11th, the first death from COVID-19 was recorded in Ireland. The following day, schools, colleges and public facilities were closed. This included all of the day services operational as part of the DOCDSS support network.

In his speech of March 17th, Taoiseach Leo Varadkar asked those in the 'vulnerable or at-risk category' to stay at home for 'several weeks'. However, the DOCDSS had pre-empted this directive and from 16th March all areas of socialisation and visitation were closed. This included visits to and from family and friends in Community and Residential Houses and Health Care facilities as well as a total cessation of activities which would normally take place in schools, Churches, Gyms and other recreational facilities.

The next day, all care homes and residential facilities were closed to visitors across Ireland. At the time of writing (June 2020), they remain closed. The closure has led to an increased pressure on families who provide care at home for their child or adult child with ID/ASD, particularly in light of advice for both this group, and those over 70 to stay indoors 'cocooned.'

2.2 The effects of COVID-19 experiences on families caring at home

> 'Parents… who are elderly and still providing care have their own physical mental, emotional and medical needs [which] results in enormous difficulties for them to continue to provide care. Currently during Covid-19 restrictions, safety measures and social distancing have enforced closure of all-day services which adds difficulties to these parents caring at home.
>
> 'We are having contact from parents over 70 years requesting letters from the service for the Gardaí, to explain why they are out walking their adult son or daughter. It is shocking to think that parents who are identified in an at risk category and should therefore be cocooned, are still providing care, often personal and intimate care, cooking washing and needing letters to explain why they are taking their adult son or daughter out for walks.' [Emer, Social Worker].

The ban on visiting was especially difficult for one family member, whose sister transitioned from a hospital to a Residential Care Home during the Pandemic. Ciara was ambivalent about the COVID-19 situation – it having brought advantages and disadvantages.

> 'To be honest I think the only reason why we are where we are at the moment is because of … if this whole COVID-19 thing wasn't happening that she'd still

> be where she is. They are … desperate to move people at the minute [her sister had been in a community medical facility for a year]. But I feel that they would not have come up with the funding this quickly otherwise.'

However, when she was offered the place, she was asked to accept without seeing it that day.

> 'At that point, the house had gone into lockdown with Coronavirus so we weren't allowed in to visit [a few days later] they had temporarily lifted the restrictions on the house so … one of us was allowed to go into the house. Now most of the residents were out at the time - there was only one resident there with two care workers so I did get an opportunity to have a look at the house and have a look at her room and that kind of thing.'

But Ciara explains that she has been very concerned about her sister's reaction to the move.

> 'She understands very little about what's going on with her. So this is the first time that she hasn't had visitors [and] she won't understand why … all of a sudden there's nobody coming. We haven't … been able to sit down and even explain to her that she could be moved. I rang her last night and I tried to explain a little bit to her but… you wouldn't know how much she's taking in.'

Cara advised the service that were tasked with moving her to explain it in terms of respite.

> 'Just to kind of approach it in that way you just tell her she's moving to a new respite house because she always loved respite [and] it will give her some kind of context into what is happening. Otherwise she is being moved and she doesn't know where or understand why really? With strangers.'

[This interview was followed up on 31.03.2020 to see how participant family member was doing. Transfer to community house had taken place and reported to be settling in well. Contact with family only by phone due to COVID-19 restrictions].

For families, when day services and schools closed it meant having full time care of their children. The restrictions clearly placed already strained families under additional pressure. However, this was not an issue raised by carers although the interviews were carried out after only four weeks of lockdown. One family was having increased difficulty managing to carry their daughter up and down stairs in their newly appointed home, as well as mobilising her. They had been waiting for a special kind of physical lift mechanism, but it had not arrived. They were also waiting on a new wheelchair.

> 'We were waiting for it about three or four weeks [this was April 10th] … but now everything has come to a standstill.' [Aleeki, Father aged mid-40s].

Laura talks of a family who have a daughter with profound ID and attendant physical disability. They share a (privately rented) three-bed apartment with two other families.

> 'There is a child who lives with her parents and two other families in a shared privately rented three-bed apartment. (as this is all they can afford). They cannot afford to buy at present and do not qualify for council housing due to Dad's income. Apparently, they are just above the cut-off point. The apartment is up three flights of stairs and the child is a full-time wheelchair user and is very heavy. There was an incident where the lift was broken, and the mum had to wait at the stairs for someone to help her lift the wheelchair up the stairs. Dad works away from home up to 3 weeks at a time so the burden of care falls to the Mam.' [Laura, Social Worker].

She continued that there was no space for the child's equipment, and that the recommended hoist was too big to fit in the apartment. This situation was exacerbated by COVID-19 which meant that as day services and schools closed, there were three families sharing a three-bedroom apartment, and no access to a garden or outdoor space.

2.3 The effects of COVID-19 on individual service users

The Directive by DOCDSS to Service Managers suggested that they should assess their ability to link families and service users via video chat services or other forms of teleconferencing.

The Individual Service Users interviewed for this study found it difficult to be out of routine but were using technology to stay in touch with friends and family.

Julie, who had been staying in contact with family and friends through What's App video calls still found life restrictive.

> 'I usually love going out to the shops … and getting the bus up the centre and all and that all stopped.' [Julie, aged mid-40s].

Miriam also used this technology.

> 'I don't live near to my family here … they WhatsApp me… and ring me and that as well.'

However, because she is now back in a residential setting, she has no nearby physical contact and feels lonely. She does not mix with the other residents as they are all considerably older.

> 'I miss having friends as well - I miss my workplace and all yeah.' [Miriam, aged early-60].

Graham hadn't seen his family for the past couple of months because of lockdown.

> ‘But we’re seeing each other on FaceTime. I find it very interesting yeah.’ [Graham, aged early-40s].

[It should be pointed out that because this research study had to be carried out by phone, only people with a Mild ID and/or ASD were able to participate. The effects of COVID-19 do not reflect the voice of those with a Moderate or Severe ID and/or ASD].

Another Social Worker, writing her reflection for this study, felt that the Pandemic had brought about the possibility of new ways of thinking on the issue of homelessness.

> ‘I am writing this in the midst of the COVID-19 pandemic. I am reading about the re-purposing of commercial residential accommodation freed up because of the collapse in economic activity. I don’t wish any of that on anybody, but it does illustrate how much accommodation is actually available in all these short term lets. Perhaps I am naïve to think that so many houses and apartments could be utilised to mitigate the housing crisis in this country and in Dublin in particular.’ [Wendy, Social Worker].

APPENDIX 3 Access to social housing in Ireland

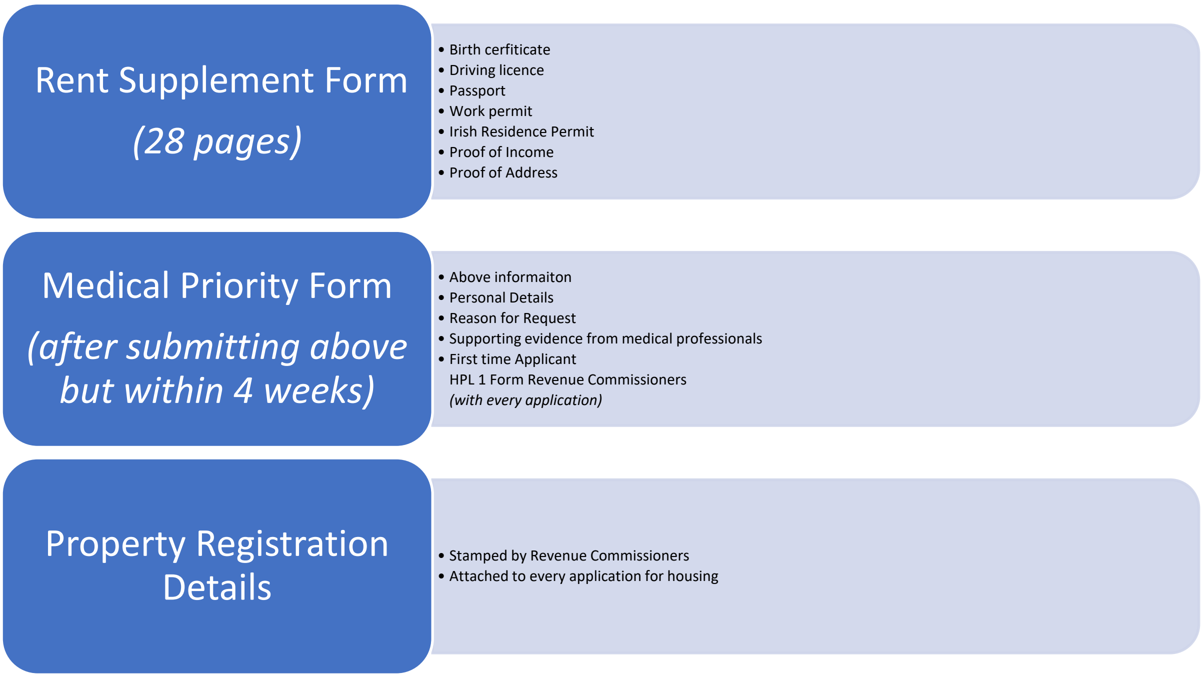
3.1 Navigating social housing

Housing in Ireland comes under the remit of, primarily, the Department of Housing, Planning and Local Government. However, other statutory agencies are involved such as the HSE (Health Service Executive), Social Inclusion, (Department Employment Affairs and Social Protection), Department of Health, as well as Local Authorities (Councils) and through them Approved Housing Bodies (AHBs). As a result, it is difficult to assess how easy or otherwise it is for a specific group to access social housing. Criteria for qualification is not universal and varies by Local Authority and AHBs. Priority bands are applied to applicants, and the first band is made up of people who are homeless. Those with a disability can also be included in this band. In 2016, 15 % of people with disabilities were renting social housing through a Local Authority or a housing body compared to 9% of all households in the general population (Central Statistics Office 2016).

3.2 Barriers to housing

Accessing social housing in Ireland is 'fraught with difficulties' (Focus Ireland 2019) and a combination of long waiting times as well as a complex system of bureaucracy leaves people (even without an intellectual disability) in need of considerable help and guidance in navigating the housing system (Focus Ireland 2019).

Diagram A3.1 Bureaucratic Requirements to Access the Social Housing Waiting List



Potential tenants must be on a Local Authority waiting list. In order to get on that list, a person must complete a number of forms. The basic one, a Rent Supplement Form, is a 28-page form. This must be accompanied by specific documentation which includes a full birth certificate, driving licence, passport, work permit and Irish

Residence Permit. Also, an applicant must provide proof of income as well as bank statements, proof of address (in the form of household bills) and/or a rent book/lease tenancy agreement.

The process of application is initially through the local authority in which the person is resident (or where the person has a proven connection). A Housing Application Form must be filled out, and while there is an 'easy read' format explaining what is involved in filling out the form, this level of accessibility is not available for the form itself which runs to more than 20 pages.

There is a banding system which operates where applicants are placed into three bands reflecting their level of need from very high to moderate:

Band 1 – Medical and Welfare and other specified Priority cases

Band 2 – Overcrowded cases and those with previously awarded medical or welfare points

Band 3 – Everyone else

To be placed on the priority list (such as Exceptional Medical Grounds) an applicant must be on the housing list first then transfer across to the priority list. The application needs the above documentation plus a report or letter on official headed paper from a medical professional who has knowledge of the person's disability. This has to be completed within four weeks of the application being received. Even without a disability of any kind, the level of bureaucracy involved makes the application process challenging.

A further requirement for first time applicants is the HPL1 form, which must be completed by the applicant and stamped by the Revenue Commissioners.

3.3 Application criteria

Dublin City Council has a set number of criteria that must be met for an individual to apply including income threshold, right to reside in Ireland and have no alternative which could meet their housing need. If there are rent arrears from a previous property, a plan must be in place to address this.

Assessment also considers the size of household, type and condition of current accommodation and any special circumstance (disability, age, medical circumstances).

To complicate matters further, there are myriad Schemes designed to assist individuals to remain in their homes which provide for assistance and physical supports, such as the Housing Adaptation Grant. There is also the Capital Assistance Scheme which is designed to provide rented accommodation for those with special needs in the form of non-repayable loans to approved bodies (AHBs).

There are other schemes, including direct and indirect leasing and funding streams for housing supports as well as Local Authority Housing and Private Rental (with or without RAS or HAP).

3.4 Waiting time

In Ireland, over seventy thousand households (n=71,858) were deemed to qualify for housing support between the thirty-one local authorities around the country. While the numbers nationally showed a decrease, nearly one-quarter (24.1%) of all social housing need is Dublin City (along with the other three Dublin local authorities) have nearly thirty thousand (n=29,698) households on their waiting list – 43.2% of the national total. Of the nearly seventy thousand (n=68,693) on the waiting list, more than two-thirds (41.4%) have been on a waiting list for more than five years (Housing Agency 2019).

APPENDIX 4 Methodology

4.1 Research design

This study uses a mixed methods approach with the predominant focus on qualitative data (interviews and reflections) backed up by quantitative analysis of data provided by the DOCDSS.

4.1.1 Data type

The qualitative element

As noted in the previous chapter, in order to address the research questions, the best practice was to take a qualitative case study approach (Flyvbjerg 2011; Yin 2012) focussing on one service – the Daughters of Charity Disability Support Services, Dublin 7, 11 and 15. This organisation seeks to provide a range of supports for individuals and with ID and/or ASD and their families to support them to live their best life. A component of these supports is the provision of guidance to successfully navigate the housing market.

The use of case studies allowed the research to focus on a 'functioning specific' (Stake 2008) – in this instance both those who experience housing challenges and the people who support them. In order to achieve this, a qualitative grounded theory approach was used with data collection centring on open-ended interviews (for individual participants and families) and personal reflections provided by support staff. This approach allowed for a broader and less restrictive concept of research design, was interactive and responsive to additional issues that the participants raised (Becker, Geer, Hughes and Strauss 1961; Maxwell 2008; Wertz 2011; Yin 1999).

As such the research could focus on phenomena in a natural setting to understand how people manage their day-to-day situations (Miles and Huberman 1994) enabling participants to describe the social meanings and processes of housing and their lived experiences (Rhodes 2000). This provided the basis of detailed contextual analysis of the experience of housing difficulty though mainly qualitative.

The quantitative element

This qualitative data was supplemented by descriptive statistics from the DOCDSS Electronic Client Record System (ECRS) Database. This data profile of DOCDSS Service Users provided a profile in terms of age, gender and housing status as well as statistics on de-congregation and respite care.

In addition, Staff Members gave an overview of numbers in homelessness according to the FEANSTA classification used in this study.

4.1.2 Sample size

The total population of people with an intellectual disability in Ireland represents 1.4% (or 67,620 persons) of the population (Central Statistics Office 2016). Recent housing statistics suggest that the homeless figures for adults in Ireland stands at 10,271 persons (Focus Ireland 2020). However, calculating the population size of adults with intellectual disability experiencing housing difficulty is affected by disputed ways of defining homelessness. The inclusive classification by FEANSTA (FEANSTA 2014) [See Appendix 1.1] has been used for this study which is broader in definition than that used by Irish Service Providers working in the area of homelessness support (Dublin Regional Homeless Executive 2009). Such variation means that progress and outcomes in studies cannot easily be compared.

The use of a case study in this instance allowed for an information-oriented sample selection where participants were selected on the basis of expectations about the information they could provide (Flyvbjerg 2011). As DOCDSS provides services to people with ID and/or ASD across the life course, positioning the research within this service provided a unique opportunity to examine the key issues that arise for both families of young adult children and individuals with ID and/or ASD.

The experience of two specific Staff Members within DOCDSS were employed. One Staff Member is part of a team who, as part of their remit, provide housing support for families and children. The other Staff supports adults to move out of the service and into independent living. The role of each Staff Member varies according to the identified needs of the person and the context of the service. Areas of intervention include assessments, linking people to resources and support, safeguarding and protection, therapeutic and support work, training/groupwork as well as advocacy. The research focussed on understanding and mapping out the experience of individuals across the life course. Pathways into and out of homelessness as experienced by these Service Users were analysed as well as the supports that are currently available and required by both populations.

In addition, six Staff Members from DOCDSS were asked to participate by way of a written guided reflection on their experiences of supporting Service Users and their families navigating the housing system.

[See Appendix 5 for Research Interviews used for this study].

4.1.3 Sample selection

Purposive sampling was used to identify specific Service Users who had experience of negotiating the housing market, either as a family with a young or adult child with ID and/or ASD or as an individual with ID and/or ASD. Five families and five individuals were identified by DOCDSS as appropriate for the study in that they had experienced homelessness or risk of homelessness. In addition, five Staff Members were asked to participate.

While purposive sampling was chosen to ensure that the sample fitted all aspects of the inclusion criteria this research project is the first time that people with an intellectual disability and their families have had an opportunity to give voice to their experiences of negotiating the housing market in Ireland. There is limited research which involves the direct participation of people with ID and/or ASD on their lived experiences of homelessness and housing difficulty. The sample size, while small and limited to one Service Provider in the Dublin area, can be seen as an information-oriented selection where participants were selected on the basis of their personal knowledge in this area (Flyvbjerg 2011).

4.2 Inclusion and exclusion criteria

In order to address the research question accurately, the following inclusion and exclusion criteria was applied:

4.2.1 Inclusion criteria

Individual participants

- Have an intellectual disability and/or autism
- Have experience of negotiating the housing market or a housing transition from residential to other housing
- Are linked in with DOCDSS at Dublin 7, 11 or 15

Family participants

- Have a family member with an intellectual disability and/or autism
- Have family-shared experience of negotiating the housing market or a housing transition with/on behalf of their family member
- Are linked into DOCDSS at Dublin 7, 11 or 15

Staff participants

- Have experience of supporting or advocating for either of the above
- Are employed by DOCDSS

2.2.2 Exclusion criteria

- All individuals are aged 18 years and over – no minors
- Participants must have the capacity to give informed consent
- Participants must not have a profound communication difficulty that would warrant participation by proxy only.

4.3 Recruitment

The Gatekeeper for this study was the Social Work Manager at the DOCDSS who oversaw access to participants through one Social Worker and one Co-ordinator of Independent Living at the service. Both have experience of supporting families and individuals negotiating housing issues and the housing market. Both have professional relationships with the participants. The recruitment was based on their professional capacity to discern if individuals and families had the capacity to give informed consent and participate fully in the research project. Informed consent is a concept which generally describes the appropriateness of the relationship between the researcher and the research participant. This concept is based on respect for the autonomy of the individual and the right to self-determination most notably in agency and the power of the individual (Miller and Boulton 2007). Gatekeepers play a crucial but often undervalued role in the conduct of social research. In providing access to participants they have to honour their ethical obligations both to their Service Users and their organisations (Singh and Wassenaar 2016). The use of 'Gatekeepers' allowed for the potential participants to be approached only as selected by Staff who had knowledge of that individual's ability to have capacity to give informed and explicit consent. In addition, it allowed for the participants to first have the research aims and objectives outlined to them by the Staff Members and for the Staff Members to tell them broadly what their participation would involve, allowing them to make a decision on whether or not to participate.

Participants, if they expressed an interest in taking part, were given a Participant Information Leaflet (PIL) and Consent Form to read and a period of one week to decide whether they wished to participate. After this time, with their agreement, they were contacted by the Research Assistant (RA) to set up a date, time and place that was convenient to them for interview. They were also advised that they could have a member of the DOCDSS team present if they wished for support during the interview.

However, because of the COVID-19 Pandemic, (see Section 2.7c) access to individual and family participants was limited to their Support Staff (in Community Residential settings) or Social Workers. Having initially agreed to interview, they were then (in the case of families) contacted by the RA and a PIL and Consent Form was issued by post with an SAE (stamped self-addressed envelope). When the Consent Form was received by the RA a time and date was set up by telephone that suited the participants.

Similarly, where individual Service Users had agreed (in advance of COVID-19 restrictions) they were approached by their Social Worker or Support Staff and asked if they would still like to participate. A PIL and accessible Consent Form was given to staff to read and explain to the Service Users, and on agreement a time and date was agreed for phone interview. Signed consent forms were collected by staff and forwarded to the RA in advance of the interviews.

In both instances prior to interview the research aims and objectives were again explained by the RA and the consent sheet was read out to the participant to ensure they understood what was asked of them. They were also asked to give recorded verbal consent to audio-recording.

4.4 Data collection

Data collection for this research comprised quantitative and qualitative elements and took place in the first half of 2020. Interviews were conducted by telephone with Service Users in the period April to June 2020 and reflections were collected from Staff Members during March and April 2020.

The qualitative elements of the research were as follows:

- Service Users - interviews with 10 participants (5 families; 5 individuals were interviewed but on analysis one was found to lie outside the specific study criteria, though they had been involved in housing transitions, none were considered risk of homelessness. As a result, this data was omitted from analysis leaving 4 Individual Service User participants)

- Staff Members – written reflections from 6 DOCDSS staff members

The quantitative element of the research was as follows:

- Statistical information from the DOCDSS Database
- Statistics on homelessness compiled by DOCDSS Staff.

This provided an overview of the numbers of people in residential services and accessing residential and housing supports from the DOCDSS in Dublin and the Greater Dublin/Leinster area. This information was provided by the (Data Protection Officer) DPO from their ECRS on request from the Research Assistant following ethical approval for the research. The Research Team had no personal access to the Database.

The Social Work team compiled data on individuals and/or families in their caseloads that met the definition of homelessness used in this study over the previous ten years. The outcomes for some of these families over that period were that they had subsequently accessed appropriate housing, but that others were no longer engaged with DOCDSS services, having had to move to a different area for appropriate housing.

4.4.1 Service user interviews

Following a Social Constructionist Grounded Theory approach, the interview schedules for this research were of necessity a series of open-ended, broad questions covering a number of topics. They included questions looking for brief biographical details, histories of housing transition and/or homelessness as well as an exploration of what ‘home’ means and the barriers, if any, to achieving that aim.

The interviews for Family Participants lasted between 38 and 57 minutes, with an average of 44 minutes and were conducted by telephone. Interviews for Individual Participants lasted between 17 and 41 minutes, with an average of 27 minutes. In the latter case, two of the participants were accompanied by their Social Worker. In the other two instances, the interviews were conducted in private. In all instances, the only input from Support Staff or their Social Worker was to provide clarity on chronological sequence of housing transitions and times spent in each scenario if needed. These inclusions are marked on the transcripts. All of the participants who agreed to take part completed the interview and consented to audio-recording.

4.4.2 Staff reflections

Similarly, the guided reflections of the Staff Members comprised a number of open-ended questions around their experience of supporting or advocating for people with ID and/or ASD and what they felt could be done to improve services for people.

All six Staff Members that were approached filled out the reflections and returned them by email with a signed consent form by separate cover.

4.5 Data analysis and anonymisation

Statistical analysis gave an overview of the numbers of people within the service in Dublin and the Greater Dublin/Leinster area, their current housing status as well as family make-up and supports utilised.

Qualitative interviews were transcribed verbatim and any identifying information was removed. Each participant was assigned an alpha-numeric code and all data was fully anonymised. Participants were assigned culturally relevant pseudonyms for inclusion in the report.

Qualitative interviews were analysed using nVivo 12 – a qualitative analysis software package produced by QRS International. The data was double coded, firstly for overall responses and then for comparative nodes across all of the groups. This allowed for recurring themes to be placed within coding frames providing a clear, synthesised and valid interpretation of the data.

4.6 Data protection and ethical issues

Prior to carrying out this study, Ethical Approval was sought from both the DOCDSS and TCD and Data Protection Impact Assessments (DPIA) were carried out for both sites as part of the ethics application. Approval was granted (19.01.2020 for DOCDSS and 03.03.2020 for TCD). All data gathered for the research was held under a rigid system of protection in accordance with GDPR regulations and only the minimum number of people involved in the research had access to the data. In addition, all computers and recording devices utilised were double encrypted and stored in a secure location.

4.6.1 Working with vulnerable groups

People with ID and/or ASD are often considered to be part of a 'vulnerable group'. A vulnerable group is defined as a number of people who share social characteristics that place them at a higher risk of poverty and social exclusion than the general population (Frolich and Potvin 2008). Having an intellectual disability remains a powerful social identity with the 'fear of difference' acting as a barrier to full engagement with the wider community (Anderson and Bigby 2016; Beart, Hardy and Buchan 2005).

Research indicates that within health and socio-economic inequalities, homelessness in an under-reported aspect of inequality for people with an intellectual disability (Oakes and Davies 2008). Furthermore, there is much discussion about research need to solicit information directly from an individual with a disability about their perception of their life and this is becoming increasingly important (Becker, Roberts, Morrison and Silver 2004; Freedman 2001).

Participation in research can be a positive and empowering experience in people who are part of a vulnerable group and participation in such research is seen to promote self-advocacy and is especially important in overcoming social exclusion (Abbot and McConkey 2006; Hall 2010).

4.6.2 Explicit consent

In order to ensure that the participants fully understood what was being asked of them, a number of checks and balances were put in place, including the use of process and explicit consent.

The two Site Co-ordinators from DOCDSS initially contacted prospective participants either by phone or in person where the latter was more appropriate. Accessible information about the study was supplied to the individual (plain English principles, supportive visuals, large font, adequate line spacing) and family participants. This information detailed the purpose of the research, the data collection methods and the nature of the commitment required from participants. Information on data management and secure storage was also provided. Additionally, participants were informed that they could change their mind at any time, withdraw without reason, refuse to answer any question and had the right to access their interview transcript if they wished. A week was allowed for review, followed by phone call by the on-site co-ordinators. Notice of verbal consent was documented and stored for the RA.

At the time of interview, the RA sought written consent to participate and the research aims and objectives, data storage and management were re-iterated. The consent was read out to the participant and the reasons given for consent. Consent was also sought for audio-recording and an explanation given as to why such recording was required and what happened to the recording after the interview finished. This consent was also sought on audio-file. The RA facilitated process consent throughout the interview – reminding the participants of their right to withdraw at any time and continually check if the participant was content to continue with the interview. This was re-iterated at the time of questions which had the potential to cause distress to the participant, such as when the RA was asking about times of homelessness.

4.7 Payment

No payment was offered for participation other than the offer to cover the costs of transportation if that was required.

4.8 Challenges with the study

4.8.1 Sample size

As explained earlier (Section 2.1a(i)), the sample size is, of necessity, small but allowed for a concise case study approach (Flyvbjerg 2011; Stake 2005; Yin 2012). The use of a qualitative Grounded Theory approach allowed for the participants to fully explore their ideas of home, and the barriers they face to achieving that aim, either for themselves or for a family member.

Following initial discussions with the on-site co-ordinators, a list of twenty-two participants was drawn up, comprising potential family and individual participants. Of that number, eight declined to participate, stating that their experience of homelessness was too distressing. One individual participant, who is a Ward of

Court, was being considered as eligible for participation but permission was refused by the Guardian ad Litem.

Five family members and five individuals agreed to participate. For the purposes of analysis, the interview of one individual Service User was omitted as it emerged following interview that they did not meet the study criteria.

4.8.2 The use of gatekeepers

There is concern over the use of Gatekeepers for any research study, and most especially with vulnerable groups, particularly where the access is provided by the Gatekeeper who provides a service to the participant. This concern is related to the potential for social control (Broadhead and Rist 1976). However, every effort was made to constantly assure participants that their access to services would not be impacted by their decision whether to participate or withdraw at any time.

4.8.3 The COVID-19 pandemic

Initial approaches to potential participants had been made by the on-site Co-ordinators in early March following the granting of Ethics Approval. By mid-March the Irish Government had announced a swathe of restrictions to reduce the spread of COVID-19. This included the closure of care homes, schools, businesses, a cessation of all non-essential travel and keeping to within a two-kilometre limit of home.

At that time, TCD also decided to cease all data collection in order to protect the welfare of participants and research staff. However, interviews that had been agreed to in person were permitted by telephone. Family interviews were conducted in the period March to April.

Following a meeting of the Scientific Advisory Committee (22.04.2020) attached to this study, it was decided that the individual Service Users who wished to participate should be facilitated to do so by phone, noting that there was concern about the viability of this approach in terms of their interaction with a person not known to them. It was agreed that the RA would phone in advance (following provisional agreement by the participants) to establish a rapport and then arrange for time of interview, if this was still agreeable to the potential participants. Seven of the participants, after an initial ‘getting to know you chat’, expressed a desire to complete the interview at the time of the first phone call. Two individual participants elected to have a ‘WhatsApp’ getting to know you chat, followed by phone interview.

In two instances, the individuals lived independently but had regular support visits from Staff. In the other instances, the individuals lived in Community Residential Houses and were supported by Support Staff as normal. The Staff in both instances facilitated participation by explaining the purpose of the research study and what their consent entailed.

The use of this method of interview meant that only people with a mild/moderate ID and/or ASD were approached for interview and the study does not include the voice of those with a more severe disability.

4.9 Quantitative data analysis

The restrictions around the time of the study also meant that a physical meeting with the Data Manager at DOCDSS could not be facilitated. However, basic demographics on Service Users were supplied by DOCDSS from their ECRS and analysed by the research team.

However, it became clear that many of the statistics that would be helpful for both an analysis of homelessness (and therefore planning for future crises) were simply not held on the database. The database follows the Statutory requirements of the NASS (formerly NIDD) and the age of the carer, for example, is not sought.

The definition of homelessness used by DOCDSS in the ECRS is also that determined by Statutory context, and therefore limited to those only without a roof over their heads. This was rectified by the Social Work Team amassing a statistical analysis from their own individual caseloads, allowing for the broader definition of homelessness used in this study.

APPENDIX 5 Interview schedules

5.1 Staff member guided reflection

As you may know, we are currently conducting a study on people with disabilities experiencing homelessness. We are asking a number of families and individuals with an Intellectual Disability or Autism to tell us about their experiences around this issue.

To help us gain a greater understanding of the work that you do, we would like to ask you to share with us some of your thoughts on the issue of homelessness for your clients.

In particular, we want to know how the housing situation is affecting individuals and families and what you think can or should be done about this. We would particularly like to know of instances were a high level of support and/or advocacy was needed to support your clients and why this is so.

We also want to know generally what you think should be done going forward to help with this issue.

We would ask that you answer the following questions.

Q1. How long have you worked in the DoCSS and what is your role?

Q2. In your opinion, what are the causes of homelessness among people with an ID and their families?

Q3. Does age, gender, type of ID, family size or location have an influence on housing for people with ID?

Q4. Can you describe what help, if any, you have given to an individual or a family in a situation of homelessness or inappropriate housing? (This could be in advocacy, bureaucracy or practical support).

Q5. Where a home has been allocated to a person with ID or their family, has that transition been successful? (If so, why and if not, what are the factors that contributed to that failure).

Q6. Can you tell us what you think of temporary housing (hostel/hub/hotel/B&B etc) solutions for people with ID (as individuals or as a family)?

Q7. What could be done to support people with ID and their families in terms of finding them suitable homes so that they can live better lives in their communities?

Q8. What do you feel works well within DOCDSS around housing?

Q9. Do you have any other comments or experiences you would like to share with us for the study?

Thank you very much for taking the time to give us your thoughts and opinions. If you have any further questions, please don't hesitate to get in touch with us.

5.2 Family service user interview schedule

Thank you very much for taking the time to meet with me. I went through the consent form with you and you signed it, which is great, thanks. I just want to double check with you that's it ok if I record what you say? If you could just say your name into the recorder for me that would be great.

Ok. So maybe we could start off by you telling me a little bit about yourself and your family?

(probe: biographical details – age, education, employment, marital status etc).

And if you don't mind now I'm going to ask you about home or housing, especially in relation to yourselves and your relative?

(probe: housing history including history of homelessness, housing transition etc).

And was anyone able to help you with that? (probe: services available and access to them)

What did you find most difficult?

(probe: lack of autonomy/control/safety etc)

What do you think is most important about getting a home for your relative?

(probe: what makes a place a home for you – safety/proximity to friends and or family/independence).

Is there anything that you think would have been helpful? Is there anything you found especially unhelpful?

(probe: what services are lacking and what is needed going forward).

Thank you very much. Before we finish up is there anything that you think I should have asked but didn't?

Are there any questions that you would like to ask me?

Thanks again for your time and your patience.

5.3 Individual service user interview schedule

Thank you very much for taking the time to meet with me. I went through the consent form with you and you signed it, which is great, thanks. I just want to double check with you that's it ok if I record what you say? If you could just say your name into the recorder for me that would be great.

Ok. So maybe we could start off by you telling me a little bit about yourself? (probe: biographical details – age, education, employment, marital status etc).

And if you don't mind now I'm going to ask you about home or housing.

(probe: housing history including history of homelessness, housing transition etc).

And was anyone able to help you with that? (probe: services available and access to them)

What did you find most difficult?

(probe: lack of autonomy/control/safety etc)

When you think of a home what does that mean for you?

(probe: what makes a place a home for you – safety/proximity to friends and or family/independence).

Is there anything that you think would have been helpful?

(probe: what services are lacking and what is needed going forward).

Thank you very much. Before we finish up is there anything that you think I should have asked but didn't?

Are there any questions that you would like to ask me?

Thanks again for your time and your patience.