Adult Autism in Homelessness: Prevalence, Experiences and Support Needs in an Irish Context - A Mixed Methods Study.

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Glossary

Several definitions for autism exist, however there is general agreement that the following characteristics are common amongst those on this spectrum - difficulties with communication, socializing, repetitive behaviours and a heightened sensory perception (WHO, 2018). For the purpose of this study, the ASIAM (2020) description of autism was adopted, denoting that 'autism is a lifelong neurodevelopmental difference which relates to how a person interacts with others and how they experience the world around them' (ASIAM 2020).

The experience of autism is multidimensional and individual to each person. Accordingly, the relationship between autism and self-perception/identity differs between individuals; for example, an individual may regard themselves as a person with autism; their autism is regarded as an experience that is separate from their personhood. However, others may consider that autism is intrinsically bound up in their sense of self and personhood so would prefer to use the term autistic person or autistic. There is increased awareness of autism as encompassing a wide spectrum of experiences, behaviours and characteristics. This has resulted in the widening of the definition of autism, which now incorporates high functioning autism or Asperger's syndrome. Reflecting this broadened definition, the term Autistic Spectrum Disorder (ASD) is frequently used, however some autistic people reject this term, as they do not regard themselves as having a 'disorder.' In this report, to represent these variances, a range of terms is used to refer to people with autism; these are; people with autism, autistic people and people with ASD.

Autistic traits

The term autistic traits denotes the characteristics or common features of autism which have been identified through personal experience, objective observation and scientific study/ screening. Commonly accepted autistic traits are; challenges with communication and social interaction, repetitive and restrictive patterns of behaviour and difficulties with sensory processing and executive function (ASIAM 2020). People with autism also commonly display strengths in relation to focused attention to detail, visual perception and lateral thinking (Dawson *et al*., 2007; Meilleur, Jelenic & Mottron 2015; Kirchner, Ruch & Dziobek 2016).

Homelessness

For the purpose of this study and in fidelity to the research methodology used, the definition of homelessness put forward by Churchard et al., (2019 p665-666) is adopted. In this definition, homelessness is:

> 'an umbrella term which covers a range of different situations. It refers to rough sleepers, that is, people who sleep or bed down in the open air, or in buildings or other places not intended for human habitation. It also includes people who do sleep in a place designed for habitation, but who do not have any legal title to their accommodation or access to any private spaces for their social relations.'

Additionally, European Typology of Homelessness and Housing Deprivation (ETHOS) scale was adopted to guide our thinking regarding the definition of homelessness. The ETHOS scale accords with the definition of Churchard et al., (2019) in classifying homelessness and housing exclusion using a range of parameters from sleeping rough to living in overcrowded conditions.

People who are homeless cite similar perceptions as those with autism as to how they are identified i.e. some people prefer to be described as people who are homeless, whereas others, who perceive the state of homelessness as part of their personhood, prefer the term . Therefore, both terms will be used to describe homeless people.

Abbreviations

ACE	Adverse Childhood Experiences
ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview Revised
ADOS	Autism Diagnostic Interview Schedule
AQ-10	Autism Spectrum Quotient Test
AQ-28	Autism Spectrum Quotient Test
DCU	Dublin City University
DOH	Department of Health (Ireland)
DSC	Dublin Simon Community
DRHE	Dublin Region Homeless Executive
ID	Intellectual Disability
IHREC	Irish Human Rights and Equality Commission
NAS	National Advocacy Service
NDA	National Disability Authority
NICE	National Institute for Health and Care Excellence
PPI	Public and Patient Involvement
RAADS-R	Ritvo Autism Asperger Diagnostic Scale-Revised
TIC	Trauma Informed Care
SCQ	Social Communication Questionnaire

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Executive Summary

Background

Autism is a lifelong neurodevelopmental difference which relates to how a person interacts with others and how they experience the world around them. The prevalence of ASD in the general population in Ireland is estimated at 1% - 1.5%. People with autism commonly experience difficulties with communication and socialising, repetitive behaviours and a heightened sensory perception. Autism may be compounded by a range of comorbidities (physical and mental health problems) and adverse life experiences which make life with autism and attendant diagnosis/ support provision more challenging. Adults with autism are at high risk of poor outcomes, including social isolation, discrimination and victimisation, difficulties attaining and maintaining employment, housing and independent living. Autism prevalence estimation is a well-documented challenge for researchers and clinicians globally due to the variability in traits across the spectrum itself and amongst different populations, screening instrument reliability and validity and the shifting diagnostic criteria.

Homelessness both arises from and contributes to vulnerability and the complex interrelationship between autism and homelessness has been under explored. Recent research by Churchard et al., (2019) estimated the prevalence rate of ASD among a cohort of long-term homeless people in the UK to be 12%. However, no previous study has examined the prevalence of autism in the homeless population in Ireland. Similarly, there is little information concerning the experiences and needs of autistic people who are homeless from their own perspectives. Appropriate assessment and service provision for people with ASD in homeless contexts has not been developed in Ireland and the ASD related knowledge and skills of practitioners in homeless services has not been examined.

This research was funded by the National Disability Authority and was conducted by a team of researchers at the School of Nursing, Psychotherapy and Community Health, Dublin City University, Ireland and University College London, UK, in partnership with the following agencies; Dublin Simon Community; Dublin Region Homeless Executive; AsIAm (Ireland's national autism charity and advocacy organisation); Gheel Autism Services and the Public and Patient Involvement (PPI) Ignite project at DCU. Public and patient involvement (PPI[1]) was an integral part of the project and two PPI representatives were involved in this regard.

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[1] The authors recognise that people with autism who are homeless are not 'patients,' however patient is the term used in health and social care research and in the context of this study the 'patients' are persons with autism experiencing homelessness who are experts by experience.

Research Aims

1. To ascertain the level of autism traits (as a measure of autism prevalence) among a representative sample of an Irish homeless population, in a defined geographical area of Dublin - Study 1.
2. To explore the lived experiences and perceptions of support services among a sample group of people with autism who have had experience of homelessness - Study 2.
3. To analyse self-perceived knowledge and skill levels of practitioners concerning ASD characteristics, needs, interventions and the support available for people with autism in homeless contexts - Study 3.

Methodology

The research methodology adopted a mixed methods approach which involved conducting three sub-studies corresponding with the three overall aims of the project.

Study 1 sought to investigate the prevalence of autistic traits among a representative sample of homeless people in Dublin. Establishing exact ASD prevalence rates among any population is a challenge; the added complexity of homelessness make this population even harder to reach. Additionally, using common approaches to interviews and ASD screening tools could potentially cause distress as well as ethical issues around asking people to participate in screening about such a sensitive and possibly previously unconsidered area. Hence, an alternative approach taken by Churchard et al., (2019), was evaluated as a sensitive, ethical, and robust research framework for the study. This methodology was based on in-depth informant interviews using screening instruments with key workers of homeless service users.

Study 1 was carried out in partnership with one of Ireland's leading not for profit homeless service providers; Dublin Simon Community (DSC). Structured screening interviews were undertaken with 11 key worker participants on behalf of their entire caseloads (n=106) of homeless clients across a representative range of DSC homeless services; emergency accommodation 40% (n = 42), supported housing 35% (n = 37), treatment and recovery services 25% (n = 27). This methodology, complying with the framework developed by Churchard et al., (2019), estimated the prevalence of autism by exploring the presence of autistic traits using the Diagnostic Statistical Manual v5 (DSM-5) Autistic Traits in the Homeless Interview' (DATHI) screening tool.

Two additional questionnaires were administered to the key workers as part of Study 1 which captured (1) demographics, health and behaviour history and (2) client characteristics and needs.

The DATHI screening questionnaire was analysed and scored manually by the researchers by rating whether autism symptoms were present for each of the seven DSM-V criteria. The four scoring options were as follows: "present" "possibly present", 'not present' or 'insufficient information" Scores on individual criteria were combined to make an estimated overall classification for each homeless person. All data was entered into an excel spreadsheet and descriptive data analysis was conducted using IBM SPSS v 25. Open ended questions were coded and analysed quantitatively.

Study 2 used narrative research methodology to examine the experiences of three people with autism (two were self-declared and one was diagnosed) in the context of homelessness. Narrative research requires a small participant sample as the aim is to uncover and illuminate lived experience in great depth. Participants were recruited across homeless services. Using narrative interviewing methods, that is, open questions concerning life with autism and homelessness, participants were encouraged to share their stories and their perspectives. The data was analysed using Riessman's (2008) narrative analysis method, which involved the initial construction of narrative cases capturing the overall trajectory of each life story, followed by analysis across the cases (cross case analysis) resulting in the generation of common themes.

Study 3 analysed self-perceived knowledge and skill levels among practitioners in homeless services in relation to the characteristics, strengths, challenges and support needs of people with ASD. Perceptions were also sought regarding the nature/quality of homeless services for people with ASD as well as practitioner training needs in this area. For this study, an online questionnaire using Qualtrics software was compiled and circulated to all homeless services in the Dublin area. The construction of the questionnaire was informed by relevant literature, guidelines and collaboration which are described in the methods section of the study. The questionnaire data was analysed using Qualtrics software and content analysis was used for the open comment answers.

Ethical approval was obtained from the Research Ethics Committee at DCU prior to the commencement of the study (DCUREC/2019/124) and an amendment to approve the online collection of data by Zoom was also subsequently approved by the DCU REC.

Key Findings

The level of autism traits (as a measure of autism prevalence) among a representative sample of an Irish homeless population, in a defined geographical area of Dublin (Study 1).

Of the 106 individual cases included in the key workers caseloads, 3 individuals (2 males and 1 female) screened "present" for autistic traits on the DATHI screening questionnaire, giving a prevalence estimate of 2.8%. A further 7 clients (6 males, 1 female) screened "possibly present" for autistic traits. This gives a combined estimate of 9.4% (95% CI: 5% ± 16% (3 + 7/106) for those who screened "present" and "possibly present". Our study reported a lower prevalence estimate than recent UK studies concerning autism prevalence among homeless cohorts. The UK research focused on a more entrenched homeless and rough sleeper population, whereas this Irish study was undertaken with homeless people who had shorter duration of homelessness and who routinely engage with homeless services. The lower estimated

ASD prevalence rates among this cohort serves as a useful extension of previous ASD in homelessness research which reported higher estimates of ASD among people with entrenched homelessness of longer duration.

The lived experiences and perceptions of support services among a sample of three people with autism who have had experience of homelessness - (Study 2).

Participants experienced autism in the context of other complexities; trauma; bullying, family issues, ignorance, neglect, stigma, shame. There was evidence of adverse childhood experiences (ACE) in each of the participant narratives. The psychosocial impact of having autism was profoundly traumatic for these participants; feeling different and not understood contributed to lifelong disruptions to identity, belonging and the sense of an inner home; a place of comfort within themselves. Participants expressed distress at not being diagnosed and supported to understand their ASD at a younger age which they believed compromised their mental health in later years. Each of the participants had co-occurring addiction issues which preceded homelessness.

Study participants experienced challenges in accessing appropriate homeless services for their housing, addiction and ASD support needs. Participants perceived some homeless services as crowded, threatening and chaotic and identified lack of autism-friendly facilities, communication difficulties and perceived lack of autism sensitivity/awareness among staff. Participants found it difficult to engage with addiction services/interventions that were based on group participation and perceived these interventions as distressing and potentially threatening, given their challenges with social contexts and past experiences of bullying.

The self-perceived knowledge and skill levels among practitioners in homeless services about the characteristics, needs and support available/provided to people with autism - (Study 3).

65% of the 206 key workers who responded to this part of the study identified themselves as having ‘layperson’ level knowledge about autism. This evaluation was borne out in the findings which showed good practitioner knowledge concerning common autistic traits. However, less knowledge was evident regarding specific challenges and comorbidities among homeless people with ASD such as mental health issues, trauma (historical/present), vulnerability, and addiction. Practitioners identified themselves as under confident/lacking competence concerning assessment, communication, understanding the needs of people with ASD. 85% had received no autism related formal training and 80% of respondents called for autism specific training. Respondents highlighted challenges in accessing screening and diagnosis for adults with ASD and 92% reported that there were no specific interventions or arrangements for people with autism within their services.

Strengths

This novel research has a number of strengths. Study 1 provides new research evidence concerning estimated ASD prevalence rates among homeless populations who are engaged with homeless services. Previous studies have estimated high ASD prevalence among entrenched homeless/ rough sleepers who have complex co-morbidities and who are often not engaged with homeless services. The current research, with its focus on a population less entrenched in homelessness, expanded the population screened using the DATHI tool and confirmed that the estimated prevalence of autism was lower among a less entrenched population with more stable service access and uptake. However, the ASD prevalence estimate among the service-engaged clients was still in excess of that of the general population.

Study 2 provided rare and often poignant insights into the circumstances, struggles and strengths of people with autism in homelessness and enabled their voices to be central to the study. Study 3 surveyed a wide range of homeless practitioner knowledge and opinions as to how their own practice and that of homeless services in Ireland need to develop in relation to the care of people with ASD. Again, this level of specificity is novel and constitutes a strong contribution to research literature.

Limitations

Across the three studies, the onset and effects of COVID-19 had a serious impact, particularly in terms of participant/respondent recruitment and ongoing availability/commitment to the research inquiry. The research team and our research partners worked tirelessly to adopt creative and flexible workarounds given that both people with ASD in homelessness and busy practitioners in pandemic contexts are hard to reach groups. The COVID-19 lockdown period meant that the DATHI was conducted using online interviews with some informant participants for study 1. Although the online interviewing process complied with the DATHI structure, it cannot be known whether or how this method influenced the informant reports. The prospect of online interview certainly affected the engagement behaviour in study 2 as well as the ASD related challenges which inhibited this cohort in coming forward for interview. Nevertheless, small sample sizes are common in narrative research and the methodology of study 2 enabled the experiences and perspectives of three participants to be heard. While the findings from study 2 are not presented as representative of the wider ASD homeless population, the experiences and opinions conveyed by participants are widely cited in the literature in this regard.

People with ASD, homeless populations and those who work with them, are considered hard to reach research populations and this was evident in our study. This meant that the research methodology needed to be flexible and realistic to this context. Given that no autism screening tool has yet been developed for homeless cohorts or those with co-morbidities, a proxy tool was used for study 1. Like Churchard et al., (2019), we acknowledge that this is a potential limitation of the study, however it did enable the reporting of autism traits by informants who had strong knowledge of the homeless cohort screened.

The questionnaire in Study 3 achieved fewer responses than we would have desired; because of COVID related pressures on staff, nevertheless there was an abundance of clear information regarding homeless practitioner ASD knowledge, perceptions of service provision, training needs and recommendations.

Conclusion

This study supports the emerging evidence that people with autism experience a range of social and health marginalisation and are overrepresented in the homeless population compared with the housed population. Autism is a risk factor for entry into homelessness and an added challenge to exiting from homeless. The unique characteristics, strengths and support needs of clients with ASD are not recognised/ addressed in housing policy, strategy or housing support provision.

Early diagnosis of autism remains inadequate and screening, support and homeless prevention/intervention among adults with ASD is poor.

Practitioners in homeless services feel challenged in addressing the autism specific needs of this population and voice the need for training in order to provide skilled homeless prevention and intervention among adults with ASD. There is insufficient autism specific support available to homeless people who have ASD. Practitioners in homeless services and across interdisciplinary teams require training to support diagnosis, screening and sensitive support taking particular account of the presence of trauma, comorbidities and addiction.

Recommendations

The recommendations from the findings of the study are summarised in Table 1.1 below.

Table 1.1 Recommendations from the triangulation of studies 1, 2 and 3

Area	Recommendation	Responsibility
Service development (diagnosis)	Increase investment in diagnostic training, services and supports for ASD in childhood and adolescence (studies 1 and 2).	HSE/Dept. of Health (DOH)
Research/ Practice development (diagnosis and screening)	• Undertake further validation studies of screening and diagnostic tools for autistic adults • Develop a range of diagnostic tools to suit varying ASD populations and those with co-morbidities • Develop basic ASD screening tools that can be used by a range of practitioners (studies 1, 2 and 3).	ASD researchers, psychology departments. Research investment from DOH
Service development/	Develop evidence informed primary, secondary and tertiary prevention of	HSE/Housing agencies/NDA/ autism services. Policy

Area	Recommendation	Responsibility
research (prevention)	homelessness among autistic populations (studies 2 and 3).	development and ongoing collaboration with relevant services. Research investment
Service development (practice)	• Identify and address barriers preventing autistic homeless people from accessing relevant support services for ASD, addictions, co-morbidities and homelessness. • Ensure clear pathways to diagnosis and service provision for adults with ASD through appropriate referral pathways. • Develop cross disciplinary models of support • Provide specialist services for people with ASD where appropriate; for example mental health services, addiction services (Studies 1, 2 and 3)	HSE/ service review and development of autism policy in collaboration with relevant services/ stake holders. Ongoing investment
Service development (planning and resources)	Increase investment in Autism Friendly Environments in homeless services (Studies 2 and 3)	City councils /HSE and homeless services in collaboration with autism services/expertise
Practice development (education and training)	• Increase homelessness practitioner knowledge of the specific experiences, needs and strengths of people with ASD. • Support development of relevant practitioner skills and evidenced based approaches and interventions (for example; psychologically informed environments, trauma informed care). (Studies 2 and 3). • Develop continuous training of public service workers and medical professionals related to autism spectrum disorders in order to ensure effective interdisciplinary working (Study 3)	Homeless services training (in service and accredited) Collaboration with relevant autism services training agencies/third level education

Section 1- Introduction and Literature Review

This research was undertaken by researchers at the School of Nursing, Psychotherapy and Community Health, Dublin City University, Ireland and University College London, UK, in partnership with the following agencies:

- Dublin Simon Community[2] who support individuals and families in Dublin, Kildare, Wicklow, Meath, Cavan, Louth and Monaghan. Dublin Simon provides a range of homeless supports, including prevention services, support to live independently (SLI), medium and high support accommodation, rough sleeper teams and a range of physical, mental and addiction treatment services
- The Dublin Region Homeless Executive [3] is provided by Dublin City Council as the lead statutory local authority in the response to homelessness in Dublin and adopts a shared service approach across South Dublin County Council, Fingal County Council and Dún Laoghaire-Rathdown County Council
- AsIAm [4] are the leading Autism advocacy organisation for people with Autism.
- Gheel services [5] provide a range of services for people with autism in the greater Dublin and North Kildare region.
- Public and Patient Involvement (PPI) Ignite project at DCU. Public and patient involvement (PPI) was an integral part of the project and two PPI representatives were involved in this regard.

The research examined the prevalence, experiences and support needs of homeless adults with ASD in Ireland. The perceptions and experiences of practitioners working in homeless services regarding their own level of knowledge/skills and Irish homeless service provision for this cohort were also explored. In section 1 of this report, the background and context of autism in homelessness is summarised in a literature review and overview of current policy and practice. Section 2 outlines the aims of the study and the research methodology used to address these aims, the findings from each of the studies are addressed in section 3, triangulation and discussion of the key findings across the three studies are presented in section 4. The conclusion, strengths, limitations and recommendations of the report are presented in Section 5.

1.1. Literature Review

This section provides an overview of recent literature pertaining to autism and homelessness. A range of electronic databases were used to search for relevant literature (CINAHL complete; PubMed; PsycInfo; Scopus; Social Sciences Premium Collection and Google Scholar). The review was limited to articles within the last 15 years (2005 -2020). Keywords used were autism, ASD; prevalence; experiences;

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[2] https://www.dubsimon.ie/

[3] https//www.homelessdublin.ie/

[4] https://asiam.ie/

[5] https://www.gheel.ie/

homelessness; services; key workers. Full-text articles in English, from peer reviewed publications were sought. In addition, a search was undertaken among relevant Irish government and service websites in relation to recent statistics and policy literature concerning autism and homelessness.

1.1.1. Autism

Autism is a lifelong neurodevelopmental difference which relates to how a person interacts with others and how they experience the world around them (ASIAM 2020). A number of definitions for Autism exist but there is general agreement that the following characteristics are common amongst those on this spectrum - difficulties with communication, socialising, repetitive behaviours and a heightened sensory perception (WHO, 2018).

1.1.2. Establishing Autism prevalence

Despite many international epidemiological studies, the global prevalence of ASD remains unclear. It is well documented that diagnosing ASD is a difficult task due to the unique clinical and subclinical manifestations among individuals (Huerta & Lord, 2012). Historically individuals with autism may have been mis-diagnosed as having intellectual disability or schizophrenia and sensitive screening processes for ASD are a relatively recent development. (Stone, 2019). There are also differences in screening techniques, changes or broadening of the diagnostic criteria, as well as varying levels of autism awareness and knowledge among parents, professionals, and the general public (Department of Health (DOH), 2018). In the Irish context, Doyle et al., (2019) have highlighted the lack of ASD diagnostic services generally in Ireland. Diagnostic services for Irish adults with autistic traits are even more sparse than those available for children.

The prevalence of Autism in Ireland has been identified by the current study Co-PI and her colleagues as a minimum of 1% of the population (Boilson et al., 2016). However, the authors estimate that the true prevalence allowing for methodological issues is thought to be closer to 1.5%. An estimated prevalence of 1.5% has been adopted by the DOH for planning policy and services. The prevalence rate for autism was estimated at 1% worldwide by Elsabbagh et al (2012) and Tsai (2014). Prevalence estimates of ASD have increased dramatically over the last two decades, leading to claims that there is an autism epidemic, however Chiarotti & Venerosi (2020) in a systematic review, highlight that data indicate a high variability in prevalence across the world, due to methodological differences in case detection and the consistent

1.1.3. ASD, co-occurring conditions and complexities

People with autism commonly experience a range of co-morbidities and adverse life experiences which make life with autism and attendant support provision more complex. The National Disability Authority (NDA) (2018) suggests that between 40% and 69% of people who have autism also have an intellectual disability; this may further compromise a person's ability to master self-care and independence.

It is estimated that nearly 70% of people with ASD experience at least one comorbid psychiatric disorder (Buck et al., 2014), and that nearly 40% of autistic individuals may have two or more psychiatric disorders (DeFilippis, 2018); primarily depression and anxiety. Iemmi, Knapp, & Ragan (2017) consider the lifelong incidence of mental health difficulties among people with ASD to be as high as 80%. Mental health issues can result from adverse childhood experiences (ACE) (Haruvi-Lamdan, Horesh & Golan 2018) and from the challenges of living with autism (Fitzpatrick et al., 2016). ACE is defined as the presence of sexual, physical, or emotional abuse, a history of severe and enduring problems with family members, and/or the absence of close, long, and personal relationships with family members (Ressel et al., 2020). Unfortunately, the correlation between adverse childhood experiences or trauma among people with ASD is under-researched (2018), however Peterson et al., (2019) report that that people with developmental disabilities may be three times more likely to have experienced trauma than those without ASD. People with ASD are more vulnerable due to family and relationship breakdown, difficulties in communication skills, social naiveté as well as difficulties in recognising and reporting/addressing bullying or adverse experiences. High levels of bullying among adolescent students with ASD was identified in a systematic literature review by Malano et al., (2016) and research by Forrest, Kroeger and Stroope (2020). Other studies highlight that bullying, exploitation and victimisation often continues into the adult lives of people with ASD (Paterson, McKenzie & Lindsay, 2012; Lougheed & Farrell, 2013).

A more recent co-morbidity emerging in research literature concerning ASD is addiction and substance use. Butwicka et al., (2017) highlight increasing prevalence and under diagnosis of substance use among people with ASD. Lundström et al., (2011) found that participants with diagnosed ASD were six times more likely to be at risk of substance use than those without ASD. Ressel et al., (2020) highlight there are few studies ascertaining exact prevalence rates of substance use among people with ASD however some studies report the prevalence rates of co-existing ASD and substance abuse as between 19% -30% (Hofvander et al., 2009; Sizoo et al., 2010). In relation to alcohol abuse among people with ASD, prevalence rates in research range from 1.3% (De Alwis et al., 2014) to 16% (Roy et al., 2015). Sizoo et al., (2010) and Butwicka et al., (2017) identified that adverse childhood experiences among people with ASD and ADHD was a significant risk factor for developing substance abuse. This tendency to use alcohol to self-medicate and relieve anxiety among people with ASD was also observed in research by Kronenberg et al., (2015) and Clarke, Tickle & Gillott (2016).

Because of the complex presentations of these comorbidities, diagnosing co-occurring psychiatric disorders among people ASD may be challenging for mental health service providers (Hossain et al., 2020) and diagnosing ASD among people presenting with mental health/addiction issues can be equally problematic. It is essential to understand the inter-relationships between mental illness, trauma, addiction and ASD in order to ensure sensitive diagnosis and support interventions, effective policymaking and capacity building across health systems to improve social and healthcare for people with ASD (Baxter et al., 2015).

1.1.4. Socio-economic impact of ASD

Churchard et al., (2019) highlight autism-related strengths, and the fact that many autistic people lead satisfying and productive adult lives. However, these authors also indicate that people with autism are at high risk of poor adult outcomes, including social isolation, educational and occupational under-attainment, poor quality of life and increased risk of an early death. People with ASD experience greater difficulties than those without autism in attaining and maintaining employment and independent living.

A stable job provides opportunities for social interaction, financial security, and independence. Many employers are unwilling or unable to make the necessary accommodation to provide the required support to address autistic individuals' unique needs (Edelson et al., 2020). Because of the social or sensory demands of a work environment and the lack of support; many individuals on the spectrum remain unemployed, or are employed in jobs that are below their skill level and/or not personally rewarding Taylor, Henninger, & Mailick, (2015).

The recent Disability and Discrimination in Ireland report (IHREC, 2018) reveals that people with a disability are more than twice as likely as people without a disability to experience discrimination in access to housing and are 1.6 times more likely to experience housing deprivation. Thus, autistic adults are at increased risk of homelessness due to the association between Autism spectrum disorders (ASD), poor socio-economic outcomes and discrimination (Stone, 2019).

1.1.5. Homelessness

Recent government figures estimate the number of Irish homeless adults as 6,077 and homeless children at 2,651 making a total of 8,728 homeless people in Ireland in July 2020 [6] However, this national estimate does not include 'hidden homelessness' (people who are living in squats or sofa surfing), nor does it include people who are sleeping rough. Homelessness can result from a range of socio-economic factors such as poverty, loss/lack of employment, discrimination and stigma as well as personal issues such as physical/mental disability, addictions, and relationship breakdown (O Reilly et al., 2015; Schutz 2016; Sharman et al., 2016). Stone (2019) asserts that many of these challenges are also experienced by autistic people with the additional burdens of exceptionally low employment, social vulnerability, difficulty interacting with services as well as lack of diagnosis, poor service understanding of unique needs and inadequate support.

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[6] https://www.housing.gov.ie/sites/default/files/publications/files/homelessness_report_-_may_2020.pdf.

1.1.6. Prevalence of autism in homeless populations

Assessing rates of autism among homeless adults is challenging because of the existing methodological difficulties in diagnosing adult autism, as previously described, coupled with the task of accessing and engaging this hard to reach group. Various researchers have identified that autism among homeless adults frequently has not been clinically diagnosed, particularly in an era when there was little knowledge about autism. Canavan (2018) observes that late ASD diagnoses often result in lifelong social and economic exclusion. Lai & Baron-Cohen (2015) refer to this group of undiagnosed adult autistics as a 'lost generation,' because of their lack of awareness that autism may account for their many psychosocial challenges. Ascertaining autistic traits commonly involves using screening tools directly with particular individuals who have expressed a desire to be assessed for ASD or who have consented to the screening process. Involving a potentially vulnerable adult in ASD screening interviews could cause distress as well as ethical issues around asking people to participate in screening about such a sensitive and possibly previously unconsidered area (Churchard et al., 2019).

Sappok, Heinrich, & Underwood (2015) highlight that no autism screening tool has been validated for the homeless population. Nonetheless, three studies have been carried out concerning homelessness and adult autism. A small-scale study in NHS Devon (Pritchard, 2010) using service user interviews, frontline staff interviews and case note reviews revealed that of the 14 homeless men studied, 7 demonstrated strong signs of autism. A survey by Evans (2011) for the National Autistic Society in Wales revealed that 12% of autistic adults reported having been homeless at least once since leaving school. The study by Churchard et al., (2019) involving caseload screening of a UK homeless service via key worker interviews provides the most current and methodologically robust estimate of Autism prevalence in the adult homeless population. Churchard et al., (2019) and the UK team created the 'DSM-5 Autistic Traits in the Homeless Interview', (DATHI). This allowed them to gather in-depth information about the individual's presentation through interviews with key-workers. The DATHI was developed through the following sequential process: (1) consultation with experts on homelessness, including those with experience of working with autistic homeless people; (2) going through the DSM-5 criteria in detail and creating a draft interview; (3) consultation on this draft with the local Adult Autism Special interest Group, which comprises clinicians from several local adult autism assessment services; (4) piloting the measure with key workers from the homeless outreach team.

The face validity of this instrument was checked by receiving comments on drafts from homelessness and autism experts and by piloting the interview with key workers. The reliability of the DATHI was investigated by the UK team by selecting all the 'screened positive' and 'marginal' cases and a random selection of cases that had 'screened negative'. The decision to over-select positive and marginal cases, rather than take a random selection from all cases screened, was made to provide a more rigorous test of the reliability of the measure. The reliability was checked for each of the seven DSM-5 criteria and for the overall classification made, using Fleiss' kappa (Fleiss and Cohen, 1973). Criterion validity was examined exploring correlations between DATHI scores and the ASDASQ. The construct validity of the DATHI was examined by comparing those identified as having elevated autistic traits (i.e. people screening positive or marginal on the DATHI overall) with those without elevated autistic traits on the following variables reported by key workers: (1) substance misuse, (2) mental health diagnoses and (3) social connectedness.

This study by Churchard et al., (2019) estimated the prevalence of autism among a sample who were long term homeless/ rough sleepers in the UK as 12.3%. This is a staggering figure when one considers the estimated prevalence of autism in the general UK population as 1% - 1.6% (Brugha et al 2016; Rydzewska et al. 2018). Churchard et al., (2019) concluded that this 'substantially higher' figure warrants further investigation to understand the relationships between Autism and homelessness. No previous study has examined the prevalence of Autism in the homeless population in Ireland.

1.1.7. The inter-connection of autism and homelessness

Homelessness is not an outcome of autism, but of the disabling barriers autistic adults face throughout their lives' (Stone, 2019). Homelessness both arises from and contributes to vulnerability and that the complex interrelationship between autism and homelessness has been under explored. Social isolation, poor skills, lack of community understanding and support, employment disadvantage and discrimination are likely to be key reasons why autistic adults may be more at risk of homelessness (Copper et al., 2017).

AsIAm (2019) identify unemployment and family breakdown as two major precursors to homelessness among the Irish autistic population. Issues concerning employment have already been discussed. Relationship and/or family breakdown can result in the reduction of support and advocacy networks. According to Backer and Howard (2007), people with developmental disabilities are more vulnerable to becoming homeless at two critical junctures. The first occurs when a young person ages out of the care system, including foster care. When transitioning to adult services, special education and other in-school programs cease and adult service supports may not be accessible or appropriate. The second juncture occurs when parents die or are unable to support the person with autism. AsIAm (2019) highlights that only one in five of family carers plan the future care of loved ones with an intellectual disability and/or autism.

1.1.8. Challenges in transitioning out of homelessness for people with autism

Cognitive impairment, difficulties in social skills, dealing with bureaucracy and complex access systems can significantly affect an individual's ability to obtain and maintain stable housing, and to benefit from supportive services (Backer and Howard 2007). Sensory difficulties mean that many autistic people are unable to tolerate noisy, busy housing offices and accommodation where there is a disorganised, unpredictable, or chaotic atmosphere Pritchard (2010). Executive function is often impaired in people with ASD and this could make a transition to independent accommodation especially difficult (Campbell, 2015). Several studies have highlighted high rates of autistic people (often undiagnosed) who sleep rough (Pritchard, 2010; Evans, 2011). This is understandable given the confusing and overwhelming housing support environments and the desire of many people with autism to withdraw from congregations and manage their own space. Negative sequelae to entrenched homelessness for this group include deterioration of physical and mental health, addiction, bullying, harassment and sexual/physical abuse, economic exploitation and mate crime (false befriending with the aim of extortion) (Canavan, 2018; Stone, 2019). Kargas et al., (2019) assert that, paradoxically, living on the streets may offer a place of relative safety from abuse and exploitation.

1.1.9. Current care provision for adults with autism in homeless contexts

Some issues regarding care provision from the perspectives of autistic people have already been identified. In relation to statutory care provision arrangements, Canavan (2018) claims that adult autism services are minimal to non-existent in many countries. The National Advocacy Service (NAS) (2017a) highlight that although people with ASD find it difficult to cope in hostel situations they are often unable to access traditional longer term supported accommodation. There is a lack of coordinated provision between homeless and disability accommodation services; disability service providers can provide support to people in homeless services but are unable to provide accommodation. Pritchard's (2010) study found that while there is often support for people with autism and intellectual disability via adult services, those with a diagnosis of high functioning autism or Asperger Syndrome were more likely to not be in receipt of support and be at a higher risk of homelessness than the general population.

Campbell (2015) asserts that social care staff may not have adequate knowledge and skill concerning the characteristics and support needs of people with autism; often interpreting their difficulties as mental illness. When distress is exhibited through unusual or challenging behaviour, autistic people can be labelled as uncooperative, oppositional, or anti-social (Lougheed & Farrell, 2013). Therefore, people with ASD may not receive screening and support for autism and may be allocated inappropriate accommodation.

1.1.10. Recommendations and government policies relevant to Autism and homelessness

In recent times, recommendations, policies, and strategies have emerged regarding community support of people with a range of disabilities; many of these principles are applicable to autistic people experiencing homelessness. Generally, the adoption of a social model of disability is advocated which shifts responsibility for facilitating access away from the person concerned and onto society and individuals. Commentators (NAS, 2017; NDA, 2017; Canavan, 2018) advocate for the support needs of autistic people to be enshrined in national strategy with statutory guidelines and clear care pathways such as those mandated by the UK Autism Act (2009). NAS (2017) also stress the need for more autism friendly initiatives and services involving people with

Autism in the design of services to ensure that those services are effective and appropriate.

The NDA (2017) calls for specific autism services for adults in the community. Other recommendations are personalised support plans and personalised employment programmes (NICE, 2011), social skills training/psychosocial interventions (NAS, 2009) and stepped care models (Canavan, 2018). A Vision for Change [Report on the Expert Group on Mental Health] (2016) called for the provision of accessible, community-based specialist services for people with mental illness using an integrated, interdisciplinary approach. Homelessness is referenced extensively in the report, along with the risks associated with mental health, which can result in or contribute to homelessness. Unfortunately, many of these recommendations are yet to be realised. Some advancements have been made in homeless services in relation to trauma informed care, however there is little recognition of the relationship between ASD and trauma. Practitioners working in homeless services are often ill equipped to respond effectively to the unique characteristics and support needs of this population.

In the most recent housing and homelessness strategy, the government strategy Rebuilding Ireland, the National Action Plan for Housing and Homelessness (2016), sets out five steps for resolving the current housing crisis, however, disappointingly, little attention is paid to specific groups that may be vulnerable in the housing market. The Dept of Health (2012) produced the National Housing Strategy for People with a Disability 2011 - 2016 National Implementation Framework with the vision of facilitating access to appropriate housing and support services to promote independent living among people with disabilities. However, many people with autism and disabilities continue to experience difficulties with attaining housing in a competitive market. The level of complexity involved in registering for and pursuing housing is also a major barrier for people who have problems with executive functioning. This strategy has been extended to 2020.

While there has been some recent policy development encouraging person-centred care, which could be applied to this population for example; Housing First initiatives, there has been little advancement in homeless service provision or empirical research acknowledging the existence or addressing the needs of autistic homeless adults. The NDA (2018) publication Assisting People with Autism Guidance for Local Authority Housing Officers is a useful initiative in this regard as is the UK Homeless Autism toolkit resource developed by Churchard et al., (2019). [7] However, as previously outlined, much remains to be done. In Ireland two autism bills have been recently formulated however neither have yet been translated into legislation. Further, there is no explicit reference to autism on any of the Statute Books. AsIAm (2020) highlights that in order to devise effective ASD policies, policymakers need reliable evidence informed data and highlight that unlike other disabilities, there is no

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[7] https://www.homeless.org.uk/sites/default/files/site-attachments/Autism_Homelessness_Toolkit.pdf

public registry or census option for autism. AsIAm calls for an Autism Inclusion Strategy to ensure parity of access to public services for people with ASD. This 'would signal a major game changer in Ireland's journey to become truly autism-friendly.' Researchers note that the NDA has previously advised of the risks associated with having disparate strategies for each disability type.

The concluding recommendations of a Homelessness, Intellectual Disability and Autism roundtable facilitated by the National Advocacy Service (2017b) make interesting reading and are pertinent to the proposed research. This forum highlighted the 'need for research on the prevalence and experience of homelessness by people with intellectual disabilities and/or autism as well as 'training for those working in all aspects of homeless services on disability issues and awareness. Canavan's (2018) also identifies that research in this area 'is essential for continuous service improvement' and recommends that the HSE should support applied research into ASD in partnership with the relevant universities particularly in relation to screening and competent assessment. Many commentators (Lambert, 2018 and Churchard *et al.,* 2019) highlight the value of research/evidence informed primary, secondary, and tertiary prevention of homelessness among autistic populations.

1.1.11. Summary of literature review

The literature review explored relevant research and policy material concerning the nature of autism and the challenges involved in establishing autism prevalence. The review examined some of the attendant complexities of ASD for example, comorbidities, addiction, ACE and socio-economic challenges. Homelessness is a worrying sequela of autism; the inter-connection of autism and homelessness was discussed and the estimated prevalence of autism among homeless populations was analysed. Current care provision for adults with autism in homeless contexts and the challenges in transitioning out of homelessness for people with autism were areas of inquiry. The review concluded with details of government policies and recommendations relevant to Autism and homelessness.

Section 2 - Aims & Methodology

2.1. Aims

This study aimed to:

- Ascertain the level of autism traits to determine the autism spectrum disorder prevalence among a representative sample of a Dublin based homeless population - Study 1.
- Explore the lived experiences and service perceptions among a sample group of people with autism who have had experience of homelessness - Study 2.

Analyse self-perceived knowledge and skill levels among practitioners in homeless services regarding the characteristics, needs and support available/provided to people with autism. - Study 3.

The research methodology adopted a mixed methods approach; the methods used are outlined in the following sections. Public and patient involvement (PPI)[8] was a strong component of the research. PPI is research conducted 'with' or 'by' patients or members of the public rather than to, for or about them (INVOLVE, 2012). This leads to higher quality and more relevant research (Ashcroft et al., 2015). Accordingly, two PPI contributors with ASD, who had both experienced homelessness joined the research team where they played an active role in refining the research questions, research instruments, data collection, analysis and dissemination. The research advisory group consisted of the research team, partner agencies - Dublin Simon Community, the Dublin Region Homeless Executive, AsIAm and Gheel. The research involved conducting three sub-studies, which corresponded with the overall aims of the project. These studies and research methods are described below.

2.2. Study 1

This study was carried out in partnership with one of Ireland's leading not for profit homeless service providers - the Dublin Simon Community. For the purposes of this study we used the methodology developed by Churchard et al (2019) to conduct a prevalence estimate in a London based homeless population. This involved a quantitative cross-sectional study design based on a researcher administered in-depth structured interviews with key workers who provided proxy information about their client base.

The key workers were based in settings which were representative of the range of services provided by Dublin homeless services; emergency accommodation,

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[8] The authors recognise that pwd are not 'patients' but the current terminology on public involvement in health and social care research is involved in this way and in the context of this study our 'patients' are persons with disabilities who are experts by experience.

supported housing treatment and recovery services. Unlike the sample in the study by Churchard et al, (2019) who were primarily long term homeless and rough sleepers, the Irish sample had a shorter duration of homelessness, were engaging with services and in general had a more stable housing situation.

2.3. Sample and recruitment

Key workers with established relationships or good levels of knowledge about their clients were recruited via the DSC research and advocacy officer and managers of the targeted services. Information regarding the study was also provided via a participant information leaflet (Appendix 1.1). A 2-hour training session was provided to the key workers in advance of the data collection by Dr Andrew Boilson. The purpose of the training session was to provide the key workers with an overview of common autistic traits and to explain the screening tools that would be used in the one-to-one structured key worker interviews. The key worker had the opportunity to ask questions and to clarify any issues that they were unsure about. Confidentiality, anonymity and any potential ethical issues were discussed and the key worker participants gave written consent to participate in the study (Appendix 1.2).

2.4. Data Collection

The following study instruments outlined below, were administered to key workers by Dr Andrew Boilson by structured interview. The key workers provided the information by proxy on behalf of their entire eligible client caseload.

2.4.1. Questionnaire 1 – Demographics, health and behaviour history

The purpose of this questionnaire (Appendix 1.3) was to capture demographics, nature of homelessness, current accommodation situation, mental and physical health history, presence/absence of neurodevelopmental disorders, drug and alcohol history, risk to self (self-harm, self-neglect, failure to comply with medication) and risk to others/from others (violence and aggression, financial exploitation), history of health and social care service usage prior to age of 18 years, history of service relationships and current service uptake.

2.4.2. Questionnaire 2 - Client characteristics and support needs

This questionnaire (Appendix 1.4) captured background information about the clients and information relating to their current situation and relationships as perceived by the key worker as outlined below:

History of Homelessness:

- How the client had become homeless.
- Why the client had become homeless.

Relationships:

- Current relationships.
- Barriers to the client obtaining stable accommodation.

- Client's view of relationship breakdowns.

Skills & Obstacles for Independence

- How the client views their current situation.
- Goals, priorities, strengths.
- Management of practical challenges and hindering progress.

Relationships with Services & Staff:

- Establishing and maintaining rapport with staff.
- Interactions with the client.
- Maintaining and building relationships.
- Client's relationship with services.

2.4.3. Questionnaire 3 - DSM-5 Autistic Traits in the Homeless Interview (DATHI)

This screening questionnaire was used to conduct a prevalence estimate by proxy (Appendix 1.5). The DATHI has separate sections for each of the seven criteria outlined below (see below A1-B4), with general questions, accompanied by specific prompts to explore the following:

A1 - Deficits in social emotional reciprocity

A2 - Deficits in nonverbal communicative behaviours

A3 - Deficits in developing, maintaining and understanding relationships

B1 - Stereotype & repetitive movements

B2 - Insistence on sameness, inflexible adherence to routines

B3- Highly restricted fixated interests

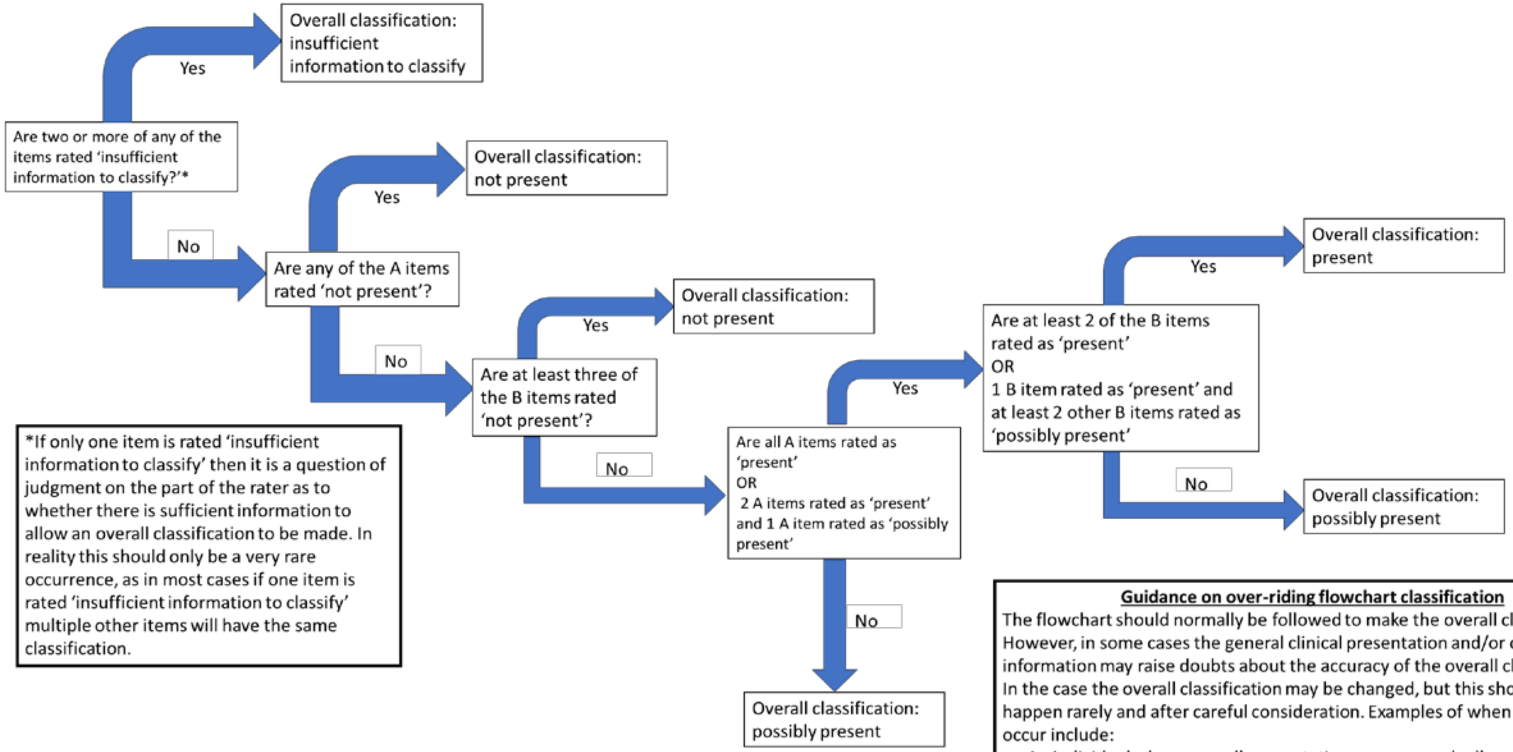
B4 - Hyper - or hyperactivity to sensory inputs or unusual interests

2.5. Data collection process

The questionnaire responses about each client were recorded by the researcher who asked structured questions to each key worker participant and recorded the information on hard copies of the research materials assigned for each client. The researcher provided specific prompts to key worker participants to guide the collection of further information regarding each client when required.

The purpose of the data collection process was to ascertain and collate the key workers' knowledge about their clients, specifically as it related to autism and related contextual information. The key workers responded to the questionnaire using their professional and personal knowledge of the service users and information from a variety of sources such as - medical, psychological and social worker reports. The data provided to the researcher by key workers was based on the key workers' professional knowledge of their clients as well as information garnered through relationships built via regular formal key worker – clients sessions over their time working/engaging with them. Just under half (n=50) of the key-worker interviews were conducted face to face with a researcher before the COVID-19 pandemic struck. The additional key worker interviews (n=56) had to be conducted remotely using Zoom due to social distancing requirements. These interviews were completed using Zoom software licensed to DCU, which was secure, encrypted and required institutional login details. Each key worker interview took approximately 3 hours to complete the information about their client caseload with variability between 15 minutes to 30 minutes' dependent on the complexity of each individual client. Figure1.1 illustrates the DATHI Coding flow chart.

Figure 1.1 DATHI Coding Flowchart



*If only one item is rated 'insufficient information to classify' then it is a question of judgment on the part of the rater as to whether there is sufficient information to allow an overall classification to be made. In reality this should only be a very rare occurrence, as in most cases if one item is rated 'insufficient information to classify' multiple other items will have the same classification.

Guidance on over-riding flowchart classification

The flowchart should normally be followed to make the overall classification. However, in some cases the general clinical presentation and/or contextual information may raise doubts about the accuracy of the overall classification. In the case the overall classification may be changed, but this should only happen rarely and after careful consideration. Examples of when this might occur include:

- An individual whose overall presentation appears markedly autistic, but who has not quite met criteria for 'Present' and has instead been put in the 'Possibly present' category. In this case it would be appropriate to re-categorise them into 'Present'.
- An individual whose overall presentation appears possibly autistic, but who has not quite met criteria for 'possibly present' and has instead been put in the 'not present' category. In this case it would be appropriate to re-categorise them into 'possibly present'.
- An individual who has met criteria for 'Present', but it is very unclear what the nature and cause of their autistic traits is. This might be seen in a very complex clinical presentation with other confounding factors such as a high level of substance misuse. In this case it would therefore be more appropriate to put them in the 'Possibly present' category.

2.6. Data analysis

2.6.1. Questionnaire 1 – Demographics, health and behaviour history

All data was entered into an excel spreadsheet and descriptive data analysis was conducted using IBM SPSS v 25.

2.6.2. Questionnaire 2 - Capturing client characteristics and support needs

All data was entered into an excel spreadsheet and descriptive data analysis was conducted using IBM SPSS v 25. The open-ended questions were coded and analysed quantitatively.

2.6.3. Questionnaire 3 - DSM-5 Autistic Traits in the Homeless Interview (DATHI)

The DATHI screening questionnaire was analysed and scored manually by the researchers by rating whether autism symptoms were present for each of the seven DSM-V criteria. The four scoring options were as follows: "present" "possibly present", 'not present' or 'insufficient information". Scores on individual criteria were combined to make an estimated overall classification for each homeless person. All data was entered into an excel spreadsheet and descriptive data analysis was conducted using IBM SPSS™ v 25. Open ended questions were coded and analysed quantitatively. All the data was checked by a second researcher at DCU to make sure that the sub scores and overall categories arrived at had no errors and had been correctly assigned. Finally all of the scores were checked by Dr Alasdair Churchard. The rules to assign each of these summary outcomes are also shown in Figure 1.

2.7. Study 2

The voices and perspectives of autistic people experiencing homelessness are seldom heard. One of the recommendations in the NDA (2017) report; Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community is to 'develop a number of case studies of people with autism without an ID documenting met and unmet need to help clarify the existing unmet need.' It was envisaged that the case study/narrative element of this research would go some way to addressing this recommendation.

This element of the study aimed to recruit, across Irish homeless and autism services, 5-10 people with autism who had experience of homelessness and invite them to contribute to the study. The methodology used for this purpose was narrative research. Narrative research is a qualitative approach, involving a small participant sample, which aims to uncover and illuminate lived experience in great depth (Riessman, 2008). A range of recruitment methods were devised; for example; recruitment by homeless/autism service staff, snowball sampling among service users who were interested in participating and advertising the study among support services for people with autism. (See appendix 2.1 for the participant information leaflet and appendix 2.2 for the participant consent form). Participant recruitment initiatives went beyond the Dublin Simon Community service to include a range of homeless and autism services across Dublin. However, participant recruitment for this element of the research project proved the most challenging. Several issues accounted for the difficulties in recruitment. As identified in the literature, there is a high percentage of undiagnosed autism in the community and in homeless contexts. Lai & Baron-Cohen (2015) highlight that many undiagnosed adults may not be aware that they have autism so service users may not have considered this study as relevant to them.

Additionally, people with autism do not commonly volunteer for interactive activities; in this research, two people who initially agreed to participate found it difficult to follow through to the interview stage. The onset of COVID-19 and ensuing government restrictions meant that face to face interviewing was not possible during the lockdown period. This created an additional barrier as potential participants either had challenges with technology or preferred not to engage in online interaction. Hence, the narratives of three participants were collected using face-to-face interviews before and after COVID-19 restrictions. Although we had desired a slightly higher response i.e. five participants, smaller sample sizes are commonly used in narrative research (Riessman, 2008; Casey, Proudfoot & Corbally 2016). In fact, Cresswell (2013) specifies that one to two cases should be used in narrative research. Findings from narrative methods are not meant to be generalizable, rather narrative research aims to uncover and illuminate lived experience in great depth (Guetterman, 2015; Vasileiou *et al.,* 2018).

The three male participants who agreed to take part in the study were from three homeless services and were recruited by key workers independently of the DATHI screening process i.e. none of the participants was included in the DATHI screening process. The three participants self-identified as having autism; one person was formally diagnosed in childhood; one person was informally diagnosed as an adult and the third participant self-diagnosed as a teenager. Using narrative interviewing methods; that is, open questions concerning life with autism and homelessness, participants were encouraged to share their stories and their perspectives (See Interview Guide, appendix 2.3).

The data was analysed using Riessman's (2008) narrative analysis method which involved the initial construction of narrative cases capturing the overall trajectory of each life story, followed by analysis within and across the cases (cross case analysis) resulting in the generation of common themes. The presentation of findings from narrative analysis involves the inclusion of longer excerpts of participants' responses in the study report to enable a richer understanding of lived experience. Participant names and other identifying material were amended to protect individual confidentiality and anonymity.

2.8. Study 3

For this study, an online questionnaire using Qualtrics software was compiled (See appendix 3.1) in order to appreciate the level of ASD related knowledge of homelessness practitioners and to capture the perceptions and experiences of staff working with people with ASD in homeless services. The construction of the questionnaire was informed by:

- NDA guidelines (2017) Models of Good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community.
- The UK Homeless Autism toolkit resource developed by Churchard et al., (2019) [9]

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[9] https://www.homeless.org.uk/sites/default/files/siteattachments/Autism_Homelessness_Toolkit.pdf

- The 2011 Northern Ireland census survey; Northern Ireland Life and Times Survey 2011 [10] which for the first time contained questions around public perceptions and knowledge of autism.

The research team added some new questions arising from the literature and from the key research questions. A small group of key workers and the research advisory group further informed the questionnaire. The PPI representatives provided input into the nature, sequencing and wording of the questions, ensuring that a range of autism features and experiences were represented. The questionnaire was piloted with six key workers and suggestions/amendments were incorporated into the tool as a result.

The questionnaire consisted of three sections; the first section; About You, captured anonymized demographic details, work context, autism training/education and self-perceived level of knowledge about autism. The second questionnaire section; About Autism asked direct questions about the nature, characteristics, prevalence, strengths/challenges of ASD to assess respondent's knowledge and perceptions. The third section; Autism and Homelessness explored respondent's self –perceived skills, knowledge and limitations in recognizing autistic traits and supporting clients who have autism. Respondents were also asked to estimate autism prevalence levels among the Irish homeless population and to give opinions regarding the quality of care provision for autistic people within their service and homeless services generally.

The questions consisted of a range of yes/no answers, Likert style questions as well as open-ended questions inviting comment. The questionnaire link was circulated by email on five separate occasions via homeless agencies and managers to key workers, case managers and project management staff working in homeless services (approx. 1000 staff).

The questionnaire received 206 responses which constituted a response rate of 20.6%. Once again the COVID-19 pandemic affected the level of responses. Many practitioners were under extreme workload pressure ensuring infection control and safety among homeless service users. Some staff were cocooning or on sick leave, other staff were asked to move between services to cover sick leave of colleagues Administrative workloads increased with contact tracing and COVID-19 monitoring work. These contextual factors undoubtedly affected the response rate.

More generally, the issue of falling response rates to questionnaires has frequently been highlighted (Galea & Tracy, 2007; Morton et al 2012). Reasons for declining participation include increased difficulty in locating and engaging eligible participants, decrease in 'volunteerism' and social participation generally, disillusionment with science and research, increased frequency of contacts by research groups, and increasing complexity of life in the 21st Century (Morton et al 2012). However, Morton et al (2012, p107) assert that studies with response rates 'as low as 20%, are able to yield more accurate results than studies

regarding the attempts made to ensure maximum participation, actual response rates and

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[10] https://www.ark.ac.uk/nilt/2012/main12.pdf

discussion of the challenges to participation are more robust indicators of the value of the

The questionnaire link remained open for 20 weeks. The questionnaire data was analysed using Qualtrics software and content analysis was used for the open comment answers.

Ethical approval was obtained from the Research Ethics Committee at DCU prior to the commencement of the study (DCUREC/2019/124) and an amendment to approve the online collection of data by Zoom was also subsequently approved by the DCU REC.

2.9. Triangulation

Results from the three-sub studies were triangulated in order to gain empirically based evidence about:

- The level of autism traits (as a measure of autism prevalence) among a representative sample of an Irish homeless population, in a defined geographical area of Dublin.
- The lived experiences and perceptions of support services among a sample group of people with autism who have had experience of homelessness
- The self-perceived knowledge and skill levels among practitioners in homeless services about the characteristics, needs and support available/provided to people with autism.

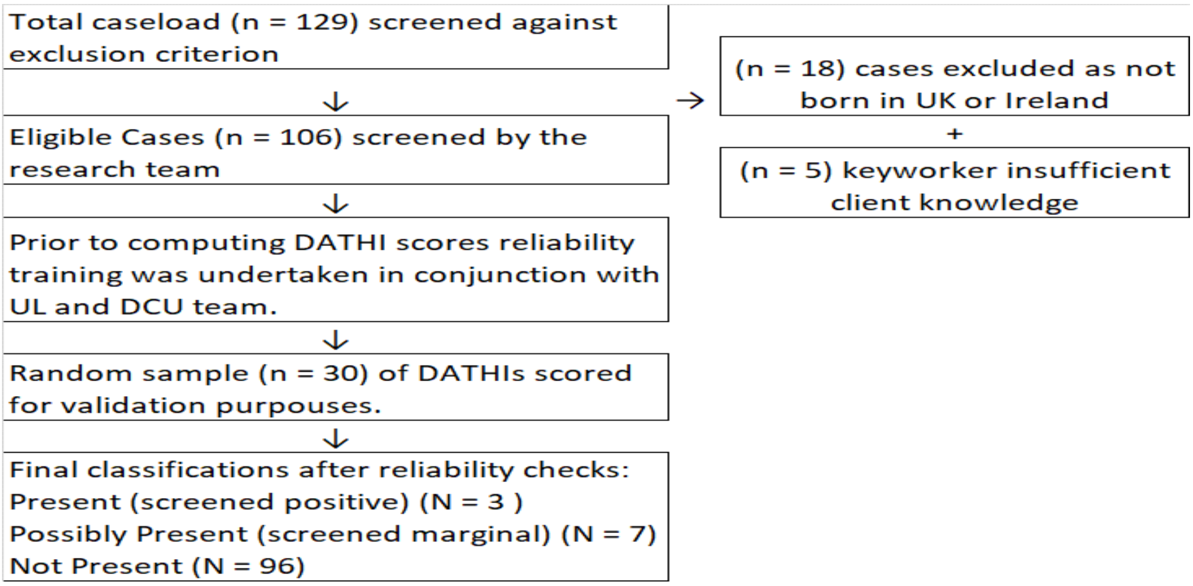
Section 3 - Results and Discussion of Studies

3.1. Study 1: The level of autism traits (as a measure of autism prevalence) among a representative sample of an Irish homeless population, in a defined geographical area of Dublin.

3.1.1. Key-worker response rates

We obtained a representative sample across the different areas of service provision offered by the Dublin Simon Community which include - emergency services, supported housing and treatment and recovery. We invited all 14 key workers who work within one catchment area in Dublin City Centre. Eleven of the 14 agreed to participate giving a response rate of 78%. Working through a structured questionnaire administered by the research team they completed questionnaires about all their eligible client caseload (n=106). The distribution of these 106 clients across the areas of homeless service provision were as follows: emergency services 40% (n = 42), supported housing 35% (n = 37) and treatment and recovery services 25% (n = 27). Seventy-eight percent (n = 83) of clients were males and 22% were females (n = 23) the screening process is provided in Figure 3.1. Key workers had been working with their client caseload on average for 15 months, (median 8.5 months). The average key worker's caseload was 10 clients, ranging from 4 – 11 clients.

Figure 3.1 Irish Autism Homelessness Screening



Total caseload (n = 129) screened against exclusion criterion

(n = 18) cases excluded as not born in UK or Ireland

+

(n = 5) keyworker insufficient client knowledge

Eligible Cases (n = 106) screened by the research team

Prior to computing DATHI scores reliability training was undertaken in conjunction with UL and DCU team.

Random sample (n = 30) of DATHIs scored for validation purpouses.

Final classifications after reliability checks:
Present (screened positive) (N = 3)
Possibly Present (screened marginal) (N = 7)
Not Present (N = 96)

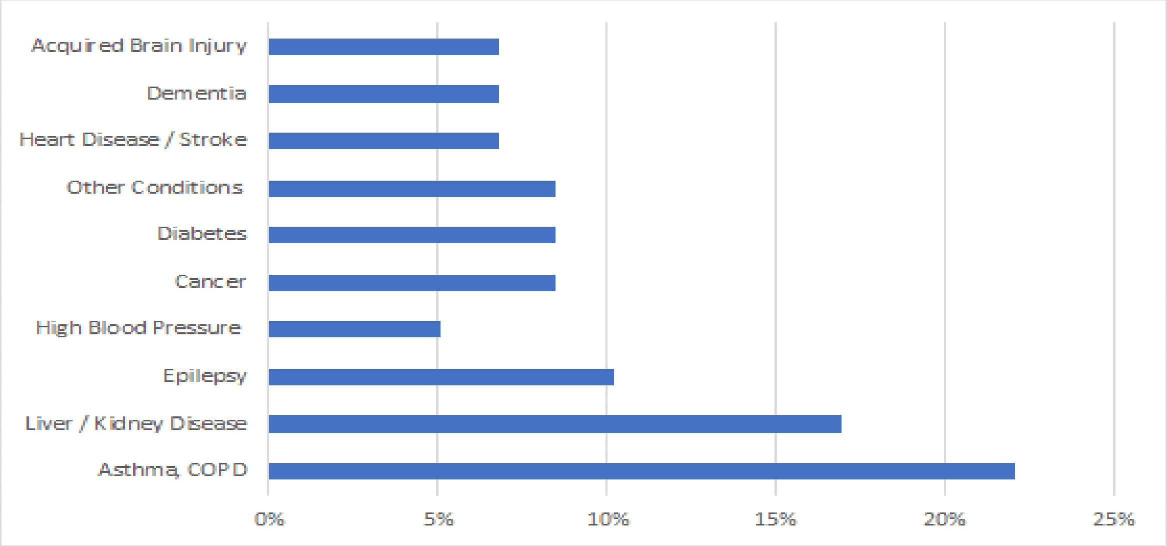
3.1.2. Questionnaire 1 and questionnaire 2 are presented together in this section

The majority of key workers 55% (n=58) met up with their clients weekly 30% met up (n=32) fortnightly and 13% (n=14) daily. Ninety-six percent of clients were white Irish (n = 102), white Traveller comprised 3% (n = 3) of the sample and black Irish comprised 1% (n = 1) of the sample. The age range of clients in this sample was 19-77 years with a median age of 45 years. The average length of time clients was homeless was 7.6 years, SD 6.8 years with a median of 5 years. There were no significant differences observed in the length of time homeless between male and female clients. Key workers were asked about their client engagement with social services up to the age of eighteen years. This data was not available for the whole sample as many clients had only become known to the homeless services when they had reached adulthood. Seventeen percent of clients had engaged services before the age of eighteen years of age, which included: adoption & foster care (n = 12, 11%), social services (n = 18, 17%), local authority care (n = 3, 3%), young offenders' institutions (n = 9, 8%) and mental health services (N = 3, 3%).

3.1.3. Physical Health

To get an insight into the client's health the questionnaire captured physical health, mental health and presence of neuro-developmental disorders as documented in the client's record/file. Fifty-six percent (n = 59) of clients had underlying health conditions. The most prevalent illnesses for the cohort of clients were pulmonary (i.e. asthma, COPD) liver, kidney and heart disease/stroke, high blood pressure, diabetes, epilepsy, dementia and acquired brain injuries. These are illustrated in Figure 3.2.

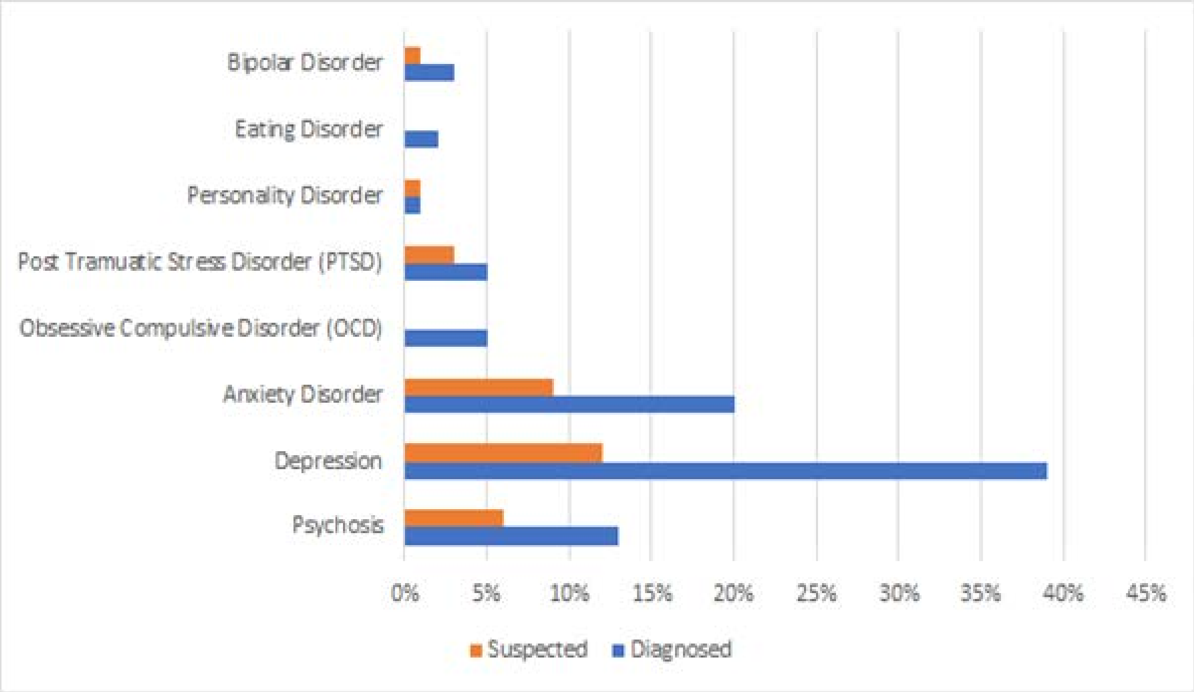
Figure 3.2 Prevalence of physical problems as reported in the client records



3.1.4. Mental Health

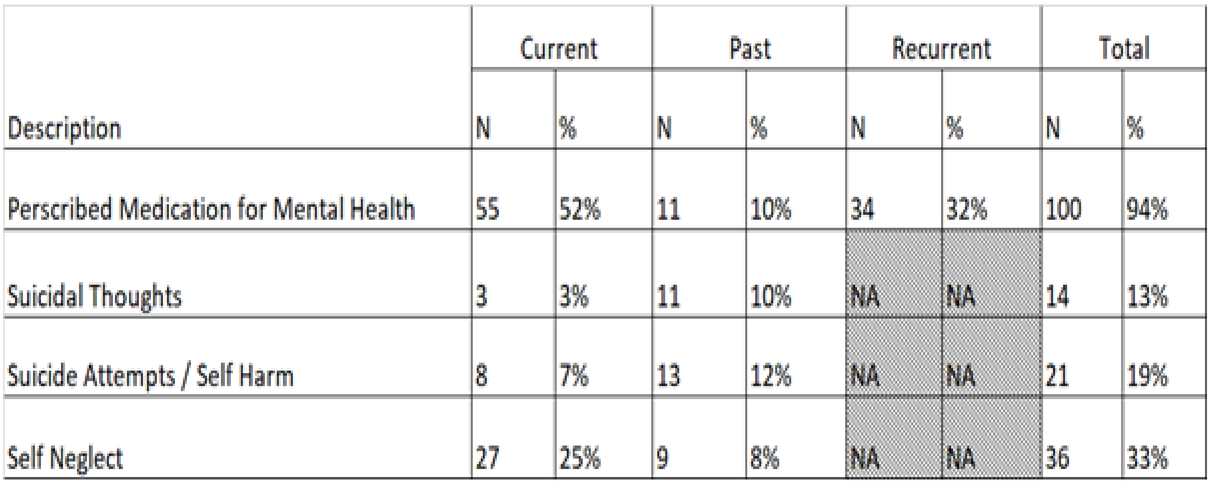
Key workers reported that overall, 41% (n = 43) of clients had a history of drug and/alcohol abuse and 53% (n = 56) had experienced traumatic events. Key workers reported that 73% (n = 77) of their clients had a history of mental health problems, either diagnosed or suspected, the breakdown of reported conditions are provided in Figure 3.3.

Figure 3.3 Prevalence of diagnosed or suspected mental health problems amongst the homeless population sampled



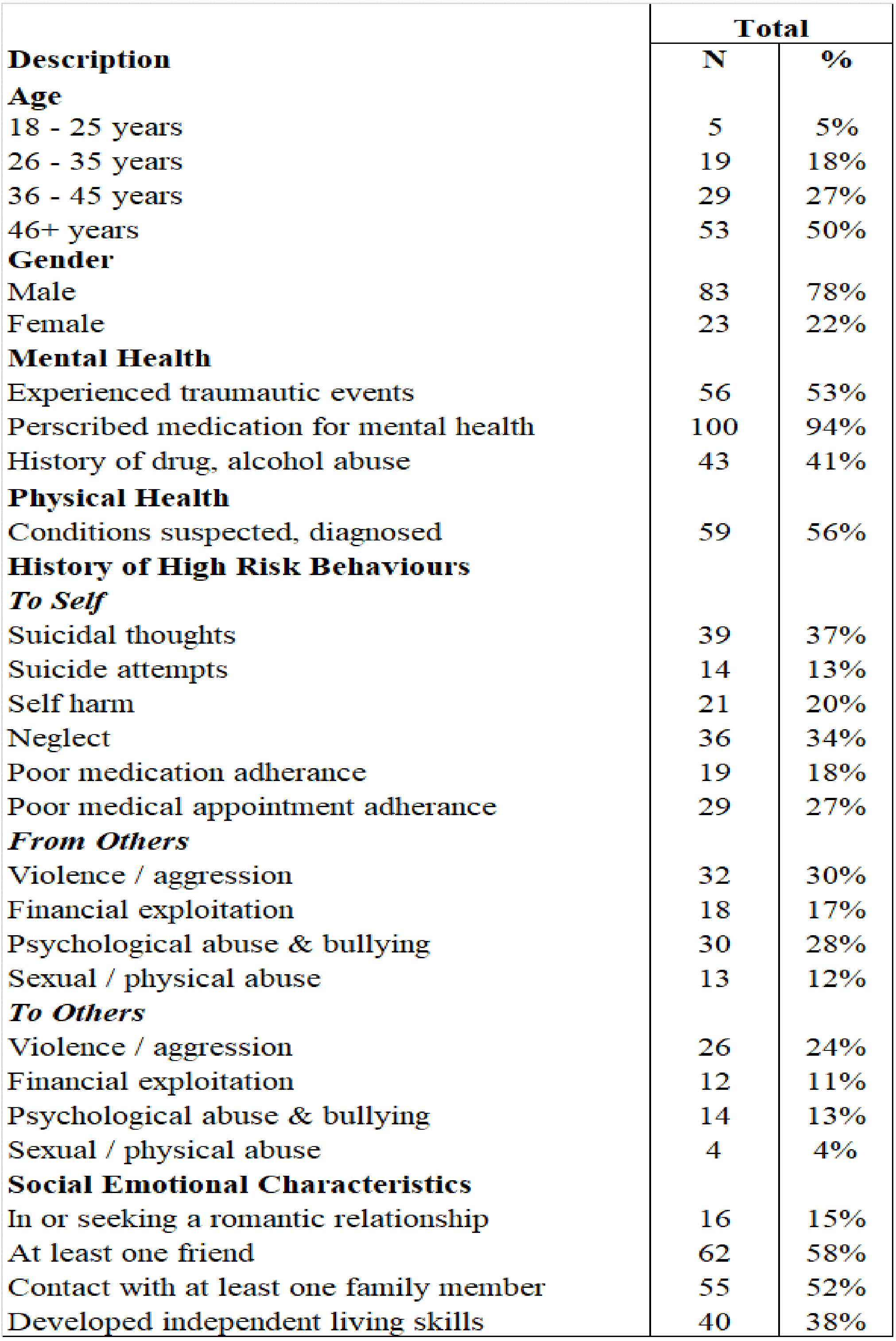
Clients' overall characteristics relating to demographics, mental, physical health, history of high-risk behaviours and social emotional characteristics is provided in Figure 3.4 and Figure 3.5.

Figure 3.4 Clients Mental Health Characteristics



	Current		Past		Recurrent		Total	
Description	N	%	N	%	N	%	N	%
Perscribed Medication for Mental Health	55	52%	11	10%	34	32%	100	94%
Suicidal Thoughts	3	3%	11	10%	NA	NA	14	13%
Suicide Attempts / Self Harm	8	7%	13	12%	NA	NA	21	19%
Self Neglect	27	25%	9	8%	NA	NA	36	33%

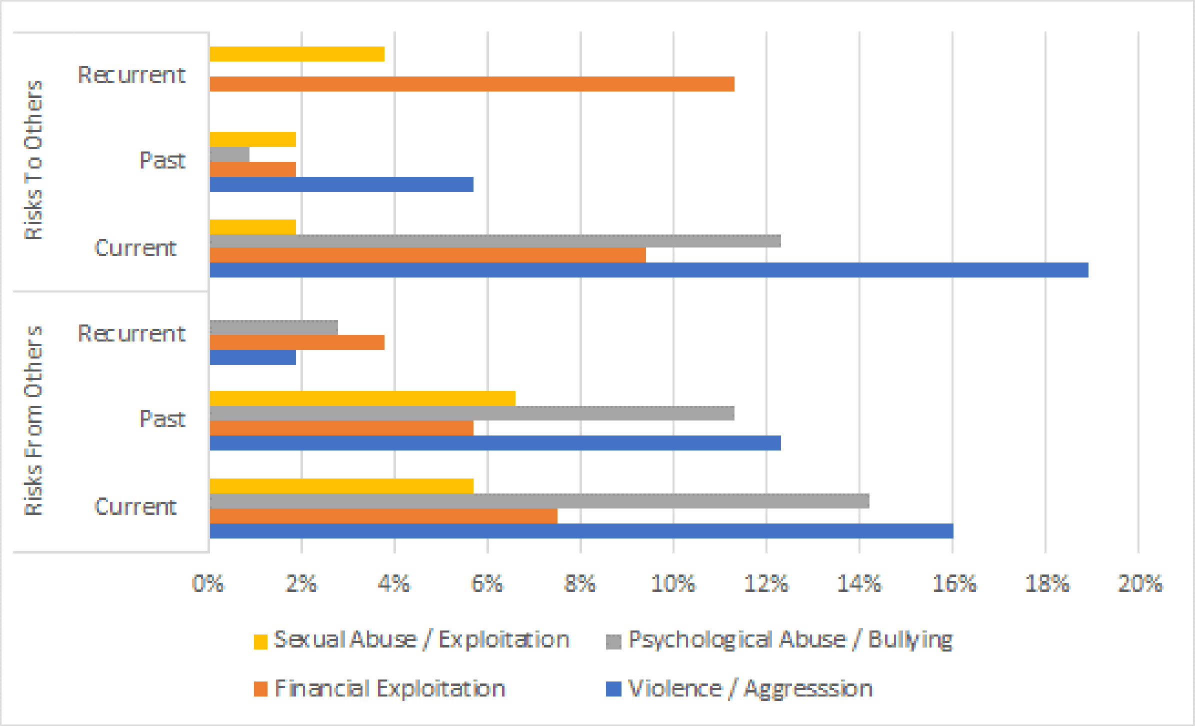
Figure 3.5 Characteristics of Keyworker Clients



Description	**Total**	
	N	**%**
Age		
18 - 25 years	5	5%
26 - 35 years	19	18%
36 - 45 years	29	27%
46+ years	53	50%
Gender		
Male	83	78%
Female	23	22%
Mental Health		
Experienced traumautic events	56	53%
Perscribed medication for mental health	100	94%
History of drug, alcohol abuse	43	41%
Physical Health		
Conditions suspected, diagnosed	59	56%
History of High Risk Behaviours		
To Self		
Suicidal thoughts	39	37%
Suicide attempts	14	13%
Self harm	21	20%
Neglect	36	34%
Poor medication adherance	19	18%
Poor medical appointment adherance	29	27%
From Others		
Violence / aggression	32	30%
Financial exploitation	18	17%
Psychological abuse & bullying	30	28%
Sexual / physical abuse	13	12%
To Others		
Violence / aggression	26	24%
Financial exploitation	12	11%
Psychological abuse & bullying	14	13%
Sexual / physical abuse	4	4%
Social Emotional Characteristics		
In or seeking a romantic relationship	16	15%
At least one friend	62	58%
Contact with at least one family member	55	52%
Developed independent living skills	40	38%

Key workers reported that some clients with mental health difficulties had experienced violence and aggression from others and had also been violent and aggressive towards others. Figure 3.6 provides a breakdown for all classifications of risks from and to others for all the clients with suspected and diagnosed mental health issues.

Figure 3.6 Clients Identified with Mental Health Problems Risks from and To Others



3.1.5. Neuro-Developmental Disorders

This data found that 16% (n = 17) of the overall client sample had a diagnosis or were suspected of having an underlying neuro-developmental disorder (Autism, Attention Deficit Hyperactivity Disorder, Intellectual Disability, Dyslexia and Dyspraxia). Four clients were suspected of having an underlying autism spectrum disorder which were undiagnosed. These results are illustrated in Figure 3.7.

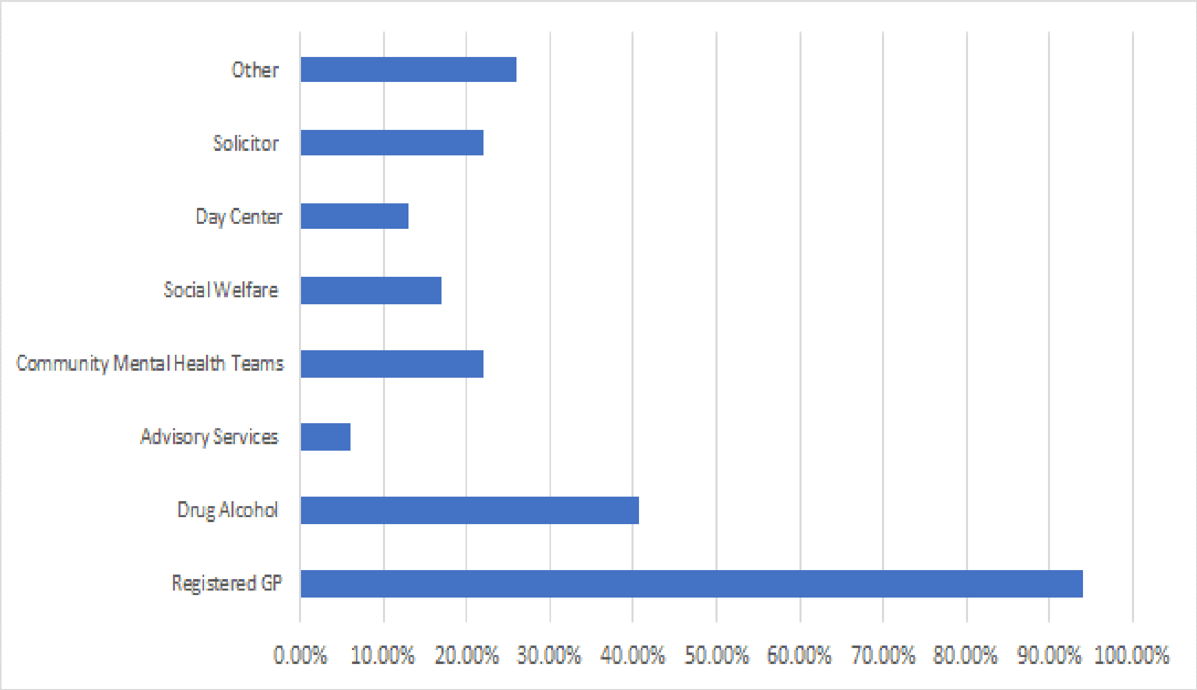
Figure 3.7 Diagnosed, and suspected Neuro-Developmental Disorders

	Diagnosed (Total)		Suspected (Total)		Not Applicable (Total)		Grand Total	
Neuro-Developmental Disorder	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Autism / Aspergers	0	0%	4	4%	102	96%	106	100%
ADHD	3	3%	3	3%	100	94%	106	100%
Intellectual Disability	3	3%	2	2%	101	95%	106	100%
Dyslexia / Dyscalculla	3	3%	0	0%	103	97%	106	100%

3.1.6. Service Utilization

Ninety four percent of clients (n = 100) were registered with a GP. Two in every five (n = 43, 41%) were engaged with drug and alcohol services and 22% were engaged with community health mental teams (n = 23). Other services which clients (n = 28, 26%) engaged with were Community Employment (CE) schemes, homeless action teams, probation officers and counsellors, psychiatrists. See figure 3.8.

Figure 3.8 Client engagement with health and social services

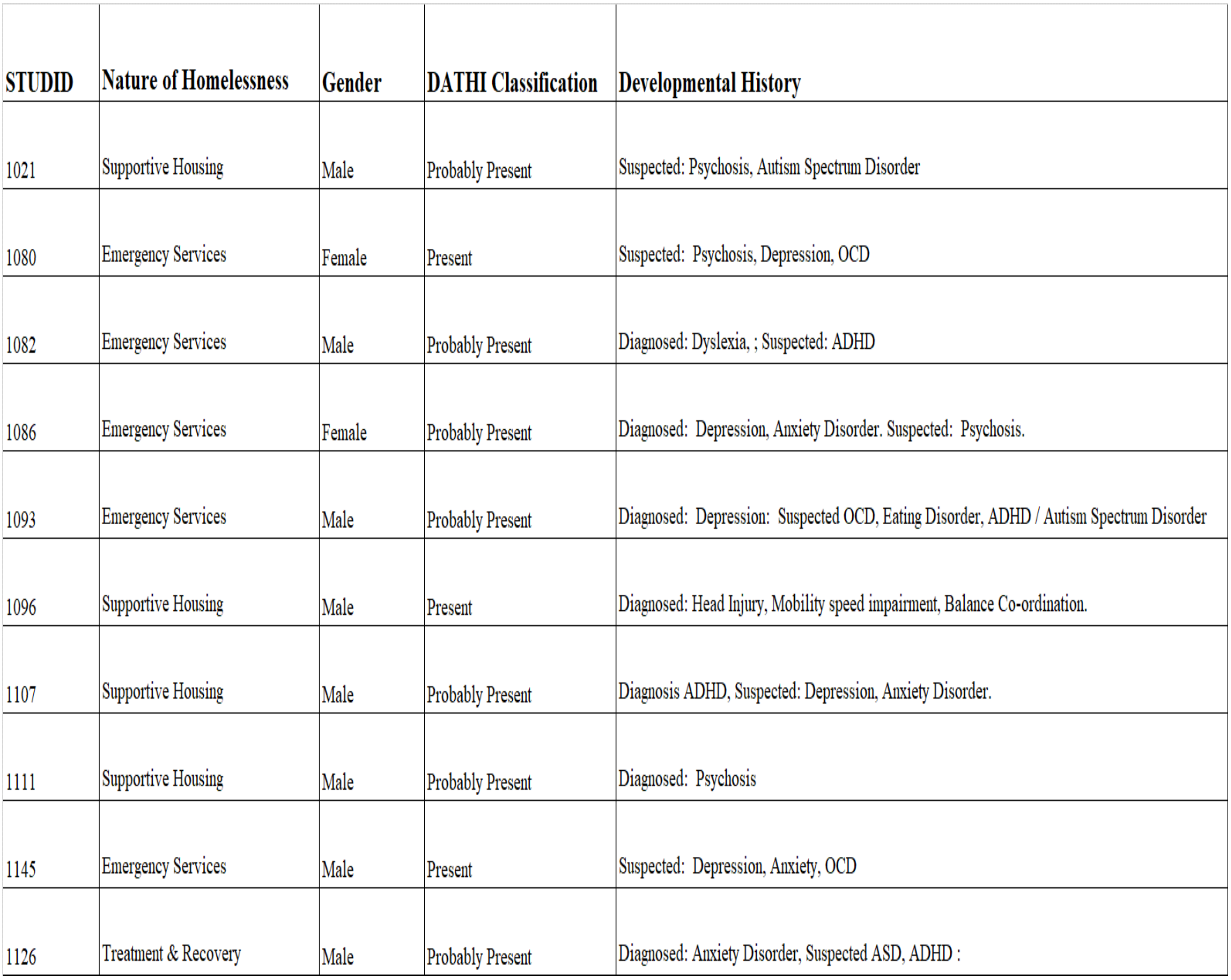


3.1.7. Questionnaire 3 - DSM-5 Autistic Traits in the Homeless Interview (DATHI)

Eleven key workers provided proxy information on behalf of 106 individual homeless clients. Of the 106 clients included in the screening, 3 individuals (2 males and 1 female) screened "present" for autistic traits, giving a prevalence estimate of 2.8%. These 3 individuals were correctly also identified in the key worker questionnaire as having suspected autism. One additional person who was also identified as a suspect ASD case via the key worker questionnaire did not screen positive on the DATHI. This client did however have a confirmed diagnosis of schizophrenia.

A further 7 clients (6 males, 1 female) screened as "possibly present" for autistic traits giving a total prevalence estimate of 9.4% (95% CI: 5% - 16% (3 + 7/106) for those who screened "present" and "possibly present" for autistic traits. Figure 3.9 illustrates the profile of those who screened "present" or "possibly present".

Figure 3.9 Profile of the clients identified by the DATHI (Present & Possibly Present)



STUDID	Nature of Homelessness	Gender	DATHI Classification	Developmental History
1021	Supportive Housing	Male	Probably Present	Suspected: Psychosis, Autism Spectrum Disorder
1080	Emergency Services	Female	Present	Suspected: Psychosis, Depression, OCD
1082	Emergency Services	Male	Probably Present	Diagnosed: Dyslexia, ; Suspected: ADHD
1086	Emergency Services	Female	Probably Present	Diagnosed: Depression, Anxiety Disorder. Suspected: Psychosis.
1093	Emergency Services	Male	Probably Present	Diagnosed: Depression: Suspected OCD, Eating Disorder, ADHD / Autism Spectrum Disorder
1096	Supportive Housing	Male	Present	Diagnosed: Head Injury, Mobility speed impairment, Balance Co-ordination.
1107	Supportive Housing	Male	Probably Present	Diagnosis ADHD, Suspected: Depression, Anxiety Disorder.
1111	Supportive Housing	Male	Probably Present	Diagnosed: Psychosis
1145	Emergency Services	Male	Present	Suspected: Depression, Anxiety, OCD
1126	Treatment & Recovery	Male	Probably Present	Diagnosed: Anxiety Disorder, Suspected ASD, ADHD :

3.1.8. Discussion of Study 1

We sought to investigate the prevalence of autism in the homeless community in an Irish context using the protocol developed by the UK study conducted by Churchard *et al.,* (2019). We screened a representative sample of the homeless population in Dublin across the three main areas of service provision, including - supported housing, emergency accommodation and treatment and recovery**.** Our study estimates a prevalence rate of 2.8%. This is considerably lower than the prevalence estimate reported in the UK study which returned a prevalence estimate of 12%. A combined prevalence estimate of present and possibly present in our current study would give a total estimate of 9.4% whereas in the UK a combined estimate of present and possibly present is closer to 20%. This indicates that the estimated rate of autism prevalence in the homeless population in the UK is approximately double the rate in Ireland. It is not clear why the rates in the UK appear to be higher but it is unlikely to be due to methodological issues, as we worked very closely with Dr Churchard in conducting the research and adhered to the same study protocols. The differential in the estimate is more likely to relate to the composition or profile of the sample across the two regions. For example, the UK study population were homeless for longer with the average duration of homelessness of 12 years, versus 7.6 years in Ireland. In addition in the UK study 43% of the sample were considered street homeless (rough sleepers), 19% were in homeless hostels, 9% living in independent housing, 9% had semi-independent accommodation and 8.5 % were from a prison population whereas the sample in Dublin did not comprise any individuals who would be considered street homeless and would be considered a relatively more stable population with emergency services comprising 40%, supported housing comprising 35% and treatment and recovery services comprising 25% of the sample. This indicates that the population sampled in the UK study appear to be a more vulnerable population with possibly greater mental health challenges and underlying neurodevelopmental problems.

To our knowledge, there have not been any studies undertaken which have explored service provision for people with autism who are homeless in Ireland either in the peer reviewed literature or grey literature. However, it is important to consider the structure and topology of homeless services provided to clients in the UK and Ireland when evaluating prevalence rates from a sampling perspective. The distinction between emergency and temporary accommodation is used interchangeably in some cases. As in several European countries, a clear line between 'emergency' and 'temporary 'accommodation does not exist in the UK. What is 'emergency' accommodation in Ireland is referred to as 'temporary' accommodation in the UK. Larger towns and cities in the United Kingdom have moved away from provision of emergency shelter towards a greater use of temporary supported housing.

Outreach teams are primarily designed to connect people living rough with other services, ranging from emergency accommodation through to Housing First are largely, but not universally, confined to urban areas.

In Ireland and the UK these services are mainstream practice, in other European Countries while outreach rough sleeper services have a function to connect people to services, there is a stronger focus on immediate survival needs (European Observatory of Homelessness, 2018). None of the clients who screened as "present" or "possibly present" for autistic traits with the DATHI tool in our study had a prior diagnosis of autism, however all of them did have other conditions (suspected or diagnosed) such as depression, anxiety disorders, obsessive compulsive disorder.

The study highlights the high prevalence of conditions related to mental health and substance and alcohol abuse issues in the sample. Several studies have suggested that cognitive impairment may be highly prevalent among homeless adults (Backer & Howard, 2007; Burra, Stergiopoulos, & Rourke, 2009). It is likely that aspects of homelessness, such as stress, malnutrition, and environmental exposures may directly impair brain function (Depp, Vella & Twamley 2015). Anxiety and depression also featured strongly in the sample in addition to the co-occurrence of other conditions (Russell et al., 2016).

Staff employed in residential settings who may recognize cognitive impairment in residents may mistakenly attribute problematic behaviours in residents as wilful refusal to adhere to community household rules or to follow through with treatment recommendations (e.g., medical appointments), rather than symptoms of executive dysfunction and memory loss common in cognitive decline. Unfortunately, standard housing service intakes often do not provide a complete assessment of individuals' cognitive, mental health, physical wellness, and social support networks (Souza et al., 2020). The lack of specific supports in another huge issue to be addressed and the main providers of support are advocacy groups like AsIAm [11] who offer advice and support and information but they do not have a role/remit in multidisciplinary assessment. The priority focus in the homelessness service system is housing stability—assisting people to access housing and providing services that achieve housing retention and stability.

3.2. Study 2: The lived experiences and service perceptions among a sample group of people with autism who have had experience of homelessness.

3.2.1. Introduction

The three male participants who agreed to take part in the study were from three homeless services and were recruited by key workers independently of the DATHI screening process. The three participants self-identified as having autism. Using narrative interviewing methods; that is, open questions concerning life with autism and homelessness, participants were encouraged to share their stories and their perspectives. Participant names and other identifying material have been amended to protect individual confidentiality and anonymity.

3.2.2. Narrative Cases

Dezi is in his mid-60's and is involved in a range of creative activities and projects. He lives alone in independent accommodation but retains some links with a homeless service. Dezi has navigated the challenges of autism, homelessness, and addiction at various periods in his life. He remembers experiencing night terrors and tantrums as a young child. He lived with his parents and remembers being obsessed with information; particularly geography and music, as he grew up. Dezi describes his mother as abusive and violent towards him at times. Dezi reports being bullied as a child and in later life and he remains sensitive to rejection and hostility because of this. He became obsessed with horses and this progressed into a gambling addiction in his mid-teens. Dezi developed an alcohol addiction at age 17.

Dezi joined the Irish army and served in the UK for a short period as a young man. He experienced a lot of bullying but liked the order and routine of army life and feels that he developed useful survival skills. Upon leaving the army, he was homeless in the UK for a few years and on returning to Ireland Dezi continued to try to overcome his addiction. He eventually realised that the key to his well-being was to allow expression of a creativity which had been suppressed for most of his life. Dezi overcame his alcohol addiction when he was 31 and moved out of homelessness some years later to his own apartment. He was informally diagnosed with autism by a psychologist ten years ago. Although the diagnosis was late in his life, this knowledge has helped Dezi to make sense of his life, his addictions and his relationships with others.

Brian is in his late twenties and at the time of interview, was about to move out of homeless accommodation services into independent living. Brian was diagnosed with autism at age six and moved from mainstream school to a special school. He describes feeling 'very different' from other children from a young age. He remembers not wanting to be with

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[11] https://asiam.ie/

others, preferring to be in his own world and 'feeling stupid' as he had difficulties concentrating in school. He lived with his mother who started a new relationship when he was a young child. Brian recounts how his mother's partner was violent towards him. As a result, Brian was removed from this abusive situation by social services and lived with relatives nearby.

Brian describes being victimised and severely bullied by peers throughout his childhood and adolescence because he was timid and withdrawn. These traumatic experiences had a profound negative effect upon him. He started drinking alcohol at age 13 and became alcohol dependent at age 15. Brian describes a wild and self-destructive few year when his alcohol use was out of control. He was constantly on police charges and his physical health deteriorated. He became sober following his last court appearance and ensuing alcohol treatment in his early twenties. Brian has been using homeless services for several years. He feels he has made progress in managing his addiction and understanding his autism.

Jozef is in his early 40's and is a skilled tradesman who is interested in science. Jozef describes characteristic autistic behaviours that he demonstrated as a child including self-isolation and repetitive/unusual movements. He recounts feeling like a 'freak.' His parents were aware of his behaviours and difficulties and these were a source of shame and disappointment to his father, however Josef cannot remember having any assessment of these issues or his parents discussing these with him. The fact that no one helped him to make sense of his mental state/behaviour is a source of great regret and frustration for Jozef. As a teenager, Jozef read many psychology books to try to understand his 'difference' and he self-diagnosed as autistic at that time. He went to mainstream school in an Eastern European country; where he experienced some bullying; he disconnected from school at 15. When he was 15, his parents' marriage broke up and both parents moved to separate countries for work leaving Jozef and his older brother in their home country. Because Jozef was struggling, his father brought him to work with him in the building trade when he was 17. Jozef loved the routine and focus of this work, when not working he spent all his time isolated in his room on the computer. He started drinking heavily in his room. His father became involved with a new partner and asked him to move out of home. Jozef spent a few years travelling and working around Europe. His alcohol use escalated and after moving to Ireland in his early 30's he collapsed due to poor health from alcohol abuse and rough sleeping. He was picked up by homeless services and successfully completed detox and treatment. Jozef is now transitioning from long-term hostel accommodation to supported accommodation.

3.2.3. Cross case analysis findings

A cross case analysis was carried out across the three narratives using Riessman's (2008) framework. This involved examining each narrative for prevalent/significant experiences and perceptions and then comparing these findings across the three narratives to determine predominant themes. The recurring themes across the narratives were as follows:

1. 'You try to fit yourself, but it's always wrong:' early experiences of life with autism
2. The homelessness within: effects of autism on belonging
3. 'It was an obsession that gave me an identity I didn't have:' Autism and addiction
4. 'I don't function under the same wiring as you:' Autism and homeless services
5. 'It's not like here you can be separated.' Addiction treatment

These themes and findings are described in more depth in the following sections.

3.2.4. 'You try to fit yourself, but it's always wrong:' early experiences of life with autism

There are several commonalities in the narratives of the three men. They all experienced themselves to be different as children.

> 'It would have been very apparent that I was different from everyone else. I would have found it very difficult to mix with other kids…' (Brian).

Dezi described night terrors, fear and heightened sensitivity concerning other people and Jozef recounted his tendency to mis-interpret loud voices and laughing as aggressive communication.

> 'It's always like I feel under pressure with people; you try satisfying them but you don't understand what they want from you. You try to fit yourself, but it's always wrong, you have habits, you like being alone all the time' (Jozef).

Yet they did not have the opportunities/support to make sense of these differences 'I didn't know what was wrong with me before. I was in no place to be looking at it' (Brian).

> 'So, I didn't even know such things, I just thought I was some kind of freak, even maybe some mental illness or something like that. I was even angry because nobody told me. But why? I said, "Why? You should have just someday sat down with me and explain to me what the fuck is going on with me so maybe I could understand it," but during my childhood it was a complete disaster because of this. Nobody told me. If someone just told me that, it would have been better …I realised what's going on very late' (Jozef).

All three participants experienced additional childhood trauma through family breakdown, neglect and sustained bullying. As Brian recounted

> 'I was getting bullied everywhere; in the home, then I would move out of home, and I'm getting bullied out in the street. It was like there was always someone to make my life hell. It wasn't just bullying and slagging, it was intense. There were beatings and public humiliations which were put on social media. It was very humiliating at the time. It was just constant fear. I couldn't be in my home or out on the road without feeling fear' (Brain).

3.2.5. The homelessness within: effects of autism on belonging

As a result, they grew up with a sense of themselves as misfits, feeling different, not understanding interpersonal 'rules' and experiencing hostility and rejection. Dezi interpreted this sense of non-belonging and uneasiness as a form of emotional homelessness that prefigured his actual homelessness.

> 'It goes back to being born where I was and rejection and the whole lot. I fell out of the home within. I didn't know what it was then, but looking it back on it now I had no home within. I had a mother and father who I love to this day. I loved them very much. My mother was very cruel to me. I still love her. I had a house. They are the positives…..but there was no home. I never felt it from within. I became uneasy with

> myself…. As a child of 11, I remember I wanted to go to the Sahara desert and live in the Sahara desert with a bottle of milk and Calvita cheese forever and ever. I just wanted to go away. Then I would go missing from school, run away from home. In a sense that it is homelessness because you have no home to go back to. You want to run forever and ever. The homelessness travelled with me. That uncomfortable feeling with myself brought me from different places' (Dezi).

Similarly, Jozef and Brian described a sense of displacement, of being unable to find a place of stability and peace within themselves or a sense of belonging in their environments.

3.2.6. 'It was an obsession that gave me an identity I didn't have:' Autism and addiction

The relationship between autism and addiction was complex in the men/s lives. All developed addictions at an early age before they became homeless. They referred to the affordances of alcohol in relieving the anxiety and fear they carried around with them. Alcohol proved to be a potent social lubricant, enabling them to be more spontaneous and confident and softening interactions with others.

> 'It (alcohol) made me feel safe, because I was in a constant state of anxiety then and it took that away. It took that anxiety away. It gave me confidence. It gave me everything I was lacking as a human being. I wasn't the quiet young fella with autism or Asperger's syndrome anymore. I was able to function and be free. It was the solution at the time to my problem, then it became a problem itself.' (Brian).

What started as a form of self-medication, quickly spiralled into addiction. As the addictions progressed, the men became homeless.

3.2.7. 'I don't function under the same wiring as you:' Autism and homeless services

Being homeless and autistic brought many challenges. Jozef explained the contradictions between wanting to be alone and yet needing help.

> 'I went on the street, I could escape to my head again, so it was quite alright. But in the meantime, you have to eat [laughs] and you're looking for some shelter. There is an East European community and I would meet homeless people as well, but I could not find myself with them, I just prefer to be always alone…..' (Jozef).

Dezi referred to the hostility and rejection he encountered when he became homeless on returning from the UK.

> 'When I came back from the UK after many homeless years, I was interrogated. 'Why are you coming back here?' It was terrible. I felt it very abusive. The fear in that room if I was going to the rough sleepers unit. How can you go in there and sleep? You would rather sleep in the streets. When I got my place it wasn't too bad compared with what you had to go through to get it' (Dezi).

Dezi felt that his survival skills learned in the army helped him to navigate the homeless care system. This involved resilience, negotiation skills and having a 'character where I didn't demand. They were in charge; they were in control and I had to be a diplomat.' However, Jozef highlighted the paradox of this self-imposed withdrawal and articulating support needs.

> 'We try to be separate, don't ask too much, don't try to be too noisy, but this is such a condition where you have to be very noisy, you have to almost shake them because it's like that. If you're not asking and you do nothing, then nothing happens. … If something is wrong, you have to tell them now. But most people like me just go back, and find another way. So, if the staff don't know it, how can they respond?' (Jozef).

Dezi also identified challenges in interpretations; 'When you say something to an autistic person, 'I will see you at 3 o'clock and you are not there at 3 o'clock, they don't understand it.' For Jozef, his difficulties in processing voice tone, volume, inflection and speed caused further distress and miscommunication.

> 'If someone is talking to me, for example, if they change their voice, maybe they're excited but they talk with a lower or higher voice and it's faster, you think they are aggressive against you. And you feel the shakes and stuff, but this is above your knowledge, it's more the feelings. You know that, but you're still shaking…..You just sit there, the people are talking to you, and mostly you don't even understand what they're talking about, you just hear the level of voice. This could be the problem when you think "Maybe they don't like me," or something like that, and you just walk away and never come back' (Jozef).

Brian's experiences of homeless care provision were quite negative and he expressed a lot of anger in this regard. Brian felt that his needs were not acknowledged or understood.

> 'I need more support. I probably have more needs than your average person in that service. You have pressure from key workers. I tell them I have Asperger's; they don't know, or they don't care. They want you written off as stats. They would be pushing me to get a full-time job, and I'm like, 'It's not that simple for me.' These people have psychology master's degrees, so I doubt they don't understand. I just think they don't care… Not supporting me at all. They want to push me out, 'Go on, get a full-time job. I do it.' Fair play to you for doing it, but I don't function under the same wiring as you. If I did, I wouldn't be here in the first place' (Brian).

Conversely, Dezi found homeless services supportive once he was able to access these. He found a placement which had routine and a similar predictability to his army life. Similarly, Jozef describes staff accommodating his need for a quiet and non-chaotic environment when finding him a placement. The homeless service where Dezi was accommodated, supported him in gaining academic qualifications and nurturing his creativity. These achievements had a profound effect on his self-esteem and confidence.

> 'When I was in a hostel in 2008, I gained my first academic qualification. That room was filthy, it was scruffy, it was dirty and manky. Okay, it is your own room. In the mornings, you see the staff going round with gloves on picking up the needles and all that. This is my home. Everything I own was in this place. Anyway, I scrubbed that place. It didn't make much difference, but I got it clean' (Dezi).

It is interesting that Dezi referred to such undesirable living conditions as 'home' in contrast to his earlier depiction of feeling homeless in his family home. Dezi equated finding his creativity with 'filling an empty void' within himself and finding his 'inner home.' For Jozef, entering homeless services meant that he was able to access addiction treatment and he is proud of achieving and maintaining sobriety.

3.2.8. 'It's not like here you can be separated:' Addiction treatment

The participants highlighted many significant considerations regarding addiction support for autistic people. For example, Josef described his determination to be free from alcohol and the interpersonal challenges involved.

> 'And now I see the enemy because the enemy is alcohol, so I'm going to fight with it. I was ready. And in the very beginning it was okay, but you have to live with people there. And try to imagine how hard it was for me; for me, it was double hard. On the one hand, you have to manage all these things like addiction, and on the other you have to be with people all the time; it's not like here you can be separated. My AA meetings: can you imagine what kind of disaster when I started that? Because we are all the time with people, you're sitting with people you don't even know, and you must talk with them. But I took this like, "Right, it's one of the most important parts of this addiction treatment, and so I have to do this, I have to survive, that's it" (Jozef).

Dezi described other challenges of group therapy; for example, that of not fitting in. Dezi's experience was that he was regarded as different in the groups and 'no matter how much you identify or relate to, you still feel outside. After a meeting, people don't come to me. I go to them.' Like Jozef and Brian, Dezi struggled with large groups. He was sensitive to undercurrents and dynamics and the ever-present risk of sneaky bullying.

> 'Then I could see my bully there, the people that I ran away from all my life, the hostility. It is very hard being autistic and surviving that. Sneaky bullying, I think is the most destructive force against anybody, but somebody who is autistic can't… It is scary at times to sit for half an hour with a particular bully in the support group. I am a target. That doesn't mean I am a victim, but it is scary because if I blew my top…'What is this all about? He done nothing.' …. Nobody has seen it. You can't explain these games...you can't explain them in words and if you do… it makes no sense to anybody, but the person that delivered it knows the game. When you try and explain it, it's already in the past, you explode because there is nowhere else to explain. I am getting caught up again. I am feeling the emotion now' (Dezi).

The lack of sensitivity of staff to psychological and physical safety needs was also powerfully described by Brian. Here he questioned the taken for granted assumptions of key workers who ignored his own level of vulnerability.

> 'I was in a recovery house for the first year. A man was smoking heroin chronically, and I was basically told, 'Heroin is not your drug of choice.' It could have easily become my drug of choice and I could have OD'd in the house, and nothing would have been done about it. Well, I had autism, so I couldn't really have a confrontation with this individual who I was living with, who I was put in this small confinement with, who was using a Class A drug. A young quiet fella who is only getting sober and trying to get his shit together, put at such risk, and them being aware of this, and nothing

> being done. Why wasn't it done? They were willing to put my life at risk [sighing]…. There is a lot of anger, and a lot of resentment there, yes' (Brian).

Fortunately, Brian attended a drug day treatment programme recommended to him by a friend and found this helpful. Here he described being productively 'pushed' out of his comfort zone and, like Dezi, discovered the power of drama work in helping him to build interpersonal skills, connections, and confidence.

> 'So, I went down to that, and it was intense. It was all about behaviours, and it was all about coming out of that comfort zone….They push you to do things that you wouldn't do on your own. Last time I was sober, I was a little quiet young fella who couldn't connect with anyone. Fifteen years later, I'm thrown up in this place to play charades and do drama in front of people. I didn't know how to communicate in that way and how to let myself be free. I didn't know how to reveal myself in that way, let people see me doing things like that. The walls were up. I didn't feel comfortable in my own skin at all, but they would keep pushing you, and you would keep doing it. You would get comfortable doing it after a while. After that, my confidence grew. It was about getting comfortable in the uncomfortable. I learned how to reel in myself in that way and grow' (Brian).

3.2.9. Participant Reflections

All participants attested to the need for self-understanding and self-knowledge about their autism. Jozef was particularly distressed at not being informed of the nature of his difficulties until he researched this for himself in his teens. However, as he prepared to move to more independent accommodation, he reflected on the knowledge he has gained through his life experiences.

> 'I will have my own life, my own flat. Now I believe it's going to be better. I manage stuff, and this is important for me. I know what's going on. I know what to do if I have some problems. It used to be that I didn't know what to do, but now I know, so I know I can go to this place or ask these people….. And I hope it's going to be much better if I start being independent again, I'm even planning to go back to some schemes and who knows, maybe just normal routine and a job, and that's it. It doesn't bother me anymore, it's not like I am just sitting and "Oh my God, this happened to me, this is so bad." No, no, I'm very okay with this now. I know, and most important, I know I am not a freak….' (Jozef).

Additionally, Dezi stressed the importance of not adopting a disability or victim perspective but rather understanding the complexities of the condition and using this knowledge as a source of empowerment.

> 'I find that when you find out about yourself, then you find meaning. Meaning is very important. ..When you understand the dynamics; that it is a condition, not a disability… it may be a disability when you don't know so you are trapped and you can't understand hostilities. You can't understand people disrespecting you or not accepting you, people rejecting you' (Dezi).

Brian however, continued to find society a hostile and scary place. On the verge of moving into independent accommodation in a new area, he remained traumatised by his experiences of being bullied and his perceptions of being left vulnerable and unprotected.

> 'I've got my own place, fingers crossed. Obviously, I am a bit uncertain about the future. I am worried about things like society. Now that I have gotten sober and seeing the world for what it is, it is a very scary and worrying place….. Yes. I don't live in my own world anymore. I see people for what they are. I think I am over-aware of people, yes. ….
>
> I know what people are like. I have been harmed enough by people to pick up on that. I am still at threat. People on the street harm you, stepfathers harm you, and now, key workers are trying to harm me. Not intentionally, for their own needs, but for profit and things like that, and stats. It is still trying to harm you….' (Brian).

Dezi also commented on vulnerable young people at risk in contemporary society (those with and without autism) who he felt did not have life skills required to access/navigate complex and possibly unsupportive services.

> 'The lads and lasses with autism, I think the lads and lasses on the boardwalk and places like that, I believe they find it hard to access the services. I believe a lot of them are on the spectrum. I am not a psychologist, but maybe because they don't have the skills. I am scared for the younger kids with autism. The D4 cokeheads are not much different. I don't think they have life skills, they don't know how to negotiate' (Dezi).

All participants highlighted the importance of services and key workers being attuned to their unique needs. Like Brian, Jozef called for appropriate placement of people with autism within specific services in order to maintain physical safety and psychological well-being. Nonetheless, Jozef was anxious to point out that although people with autism have special needs, they don't need 'special treatment.' He believed that people with ASD should be subject to a range of expectations in order to prevent isolation and to help them to achieve their potential.

> 'I believe people must be from time to time a little bit pushed. Don't get me wrong, I don't say all the time, but sometimes a small push is good because it activates you. You have to be with other people, for example. You try to always find some excuse to not do this, at the end of the day try to just walk away. I'm not talking about everyone, because it's different levels. For someone who is really autistic, it's different and if you get pushed too much, it feels offensive. But for someone who is like me, you build our own small world, and you feel happy with this. But I also know I cannot be completely separate; I have to go out from the box from time to time. It's like, "Alright, I have to do this," and do this, and come back' (Jozef).

Brian also concluded 'It's all about action, pushing through the fears. They are not real; they are only thoughts. Generally, when you're afraid of doing things, they're just thoughts.' Dezi and Brian identified participation in the arts as powerful methods of expanding comfort zones and creativity. Dezi observed that many people on the streets are often creative and use artistic processes as meaning making and self-expression. In Jozef's view people with ASD do not need ‘special treatment’ however a good key worker; someone who understands the strengths and challenges of the individual with autism, is essential.

> ‘One thing that really helps is a good key worker. Because if you find some connection with her, this key worker, things go much easier because there is some person who understands what the problem, and what kind of person this is. But people with Asperger’s don’t need special treatment, absolutely nothing like that…..Just awareness, yes. It’s not the end of the world if you know what is going on. It definitely is good when I have some support, but not too much support as well, because we don’t need this’ (Jozef).

3.2.10. Discussion of study 2

Self-understanding and diagnosis

For the study participants, the psychosocial impact of having autism was profoundly traumatic; for example, feeling different, a ‘freak’ and trying to fit in yet being aware that they were ‘wired’ differently. Not being able to understand how or why they were different contributed to lifelong disruptions to identity, belonging and the sense of an inner home; a place of comfort within themselves. Similar disruptions to a sense of identity among people with ASD was described by Cooper, Smith & Russell (2017). Jozef and Dezi in particular, stressed the importance of being able to make meaning of the experiences of autism and being able to gain a sense of coherence. Cage, Di Monaco & Newell (2018) argue that for people with ASD, a sense of belonging is vital and that personal acceptance of autism as part of one’s identity can protect against depression and anxiety. However, diagnosis and support for ASD has only improved in recent times and autism among adults frequently has not been clinically diagnosed (Lai & Baron-Cohen, 2015; Canavan, 2018; Stone, 2019). Jozef’s distress at not being diagnosed and supported with his ASD at a younger age is common among adults with autism.

There is a lack of research regarding adult experiences of late ASD diagnosis, however a UK survey by Jones et al., (2014) revealed that the most common emotion experienced by adults who eventually received an ASD diagnosis was that of relief. Like Jozef, many survey participants wished they had received their diagnosis earlier in life with the necessary

ACE and trauma

For the participants in this study, autism was experienced in the context of other complexities; trauma; family issues, ignorance, neglect, stigma, shame. There is some evidence of adverse childhood experiences (ACE) in each of the accounts. ACE was defined and discussed in relation to autism in the previous literature review. Peterson et al., (2019) also identify that youth with ASD may experience more negative psychological consequences of trauma than typically developing peers. The participants in this study, particularly Brian have been deeply traumatised by ACE. The experience of bullying within the family and environment left all three participants traumatised, fearful of authority figures, and sensitive to ‘assertive’ communication or sneaky bullies. Studies by Little (2001, 2002) showed that, compared to populations without ASD, victimization rates were four times higher among young people with ASD with up to 75% of adolescents with Asperger’s syndrome being victimized. Studies have also shown that adults with intellectual disability and autism continue to be exploited and victimised throughout their lives, particularly in homeless contexts (Paterson, McKenzie & Lindsay, 2012; Lougheed & Farrell, 2013). In our study, both Dezi and Brian experienced severe bullying in the past and appear to continue to experience/be sensitive to bullying.

ASD, addiction and addiction treatment

A further commonality among the three participants was the co-occurring addiction issues which preceded homelessness. The literature review revealed that substance use and addiction were emerging as concerns among the autistic population (Lundström et al., 2011; Roy et al., 2015). The research participants identified issues, such as anxiety and social difficulties which precipitated their alcohol abuse. A review of the literature also identifies similar predisposing factors for substance abuse among people with ASD (Kronenberg et al., 2015). Sizoo et al., et al., (2010) and Butwicka et al., (2017) identified that adverse childhood experiences among people with ASD and ADHD was a significant risk factor for developing substance abuse. ACE were present in the lives of all three study participants.

All participants identified the function served by alcohol in relieving feelings of anxiety, deflecting negative cognitions/ruminations and increasing self-confidence. This tendency to use alcohol to self-medicate was also observed in research by Kronenberg et al., (2015). Clarke, Tickle & Gillott (2016) identified the use of substances by people with ASD as a method of easing social anxiety and becoming more socially confident and spontaneous; these motivations were prevalent in this study, particularly in Brian's narrative. Jozef related that his alcohol use started when he finished work for the day and was spending unstructured time in his room. In studies by Kronenberg et al., (2015) and Lalanne et al., (2015) among people with ASD, substances were used as a means to fill time and to alleviate boredom and melancholia. It follows then, that substance use treatment can present particular challenges for people with ASD, however there is a paucity of research concerning substance treatment and approaches among this population. In the wide-ranging systematic review by Ressel et al., (2020), no intervention studies were identified. Further, there are few clinical guidelines as to how people with ASD should be assessed and treated for co-occurring addictions. Brown (2018) reports that many addiction services place conditions and make assumptions about the person's level of cognitive function, motivation and ability to self-refer. However, this position overlooks the specific difficulties in self-awareness and self-management among people with ASD. Brown (2018) asserts that lack of sensitivity to individual vulnerabilities and risk as well as inflexible practices can compromise effective treatment approaches. Brian, in his account, believed that his placement with a client who was smoking heroin placed him at considerable risk and he questioned the key worker assumption that he would not be influenced by this behaviour. Brain felt that his autism hindered him from challenging this situation.

Dezi and Jozef highlighted their difficulties in engaging in group therapy, the cornerstone of addiction treatment. It was evident from their narratives that they found communicating in groups, disclosing personal information publicly to be uncomfortable (Jozef) or felt that they didn't fit in (Dezi). Dezi recounted considerable distress around the dynamics of 'sneaky bullying', which he experienced within the group. Drake (2018) also highlighted the expectation of group engagement, particularly in AA as a barrier for people with ASD citing the difficulty in talking publicly about thoughts and feelings.

The participants' entry into homelessness appeared to be related to their alcohol addiction and/or the consequences of their addictions; for example, Jozef reported that his health deteriorated through excessive drinking and he was no longer able to work and pay rent, Brian was picking up criminal charges due to disorderly behaviour when drunk and was unable to maintain housing. Dezi was in poverty due to his addiction on his return to Ireland and could not afford housing. The relationships between addiction and autism has already been discussed, additionally there is a body of research concerning addiction as a precursor or a co-occuring negative feature of homelessness (O Reilly *et al.*, 2015; Schutz 2016; Sharman *et al.*, 2016).

ASD and homeless service support

For the three participants in this study, challenges seem to have been experienced in accessing appropriate services (Dezi) and in communication/care provision in homeless services (Jozef and Brian). A study by Kargas et al., (2019) revealed that homeless people with ASD tended to avoid engaging with homeless services due to crowded, noisy and chaotic services, which can be particularly anxiety provoking and triggering. In our study Jozef identified how he preferred being away from people except for when he needed to attend to his basic needs such as food. Kargas et al., (2019) report that people with ASD may become rough sleepers as a result of these sensory and social interaction challenges. The lack of autism-friendly facilities (Nicolaidis *et al.*, 2015; Raymaker *et al.,* 2017) has been identified as a barrier for people with ASD engaging with services, therefore people with ASD may not receive screening and support for autism and may be allocated inappropriate accommodation.

Further barriers to availing of treatment and support can occur when people with ASD are either unaware of their support needs (Lai & Baron Cohen, 2015) or are reluctant to disclose these because of stigma, mistrust, fear or shame (IHREC, 2018; Stone, 2019). Jozef, in his wider narrative, referred to how he and other autistic people he had encountered in homeless services found processing others communication difficult and often struggled to verbally articulate their own needs. As a result, he, and other people he suspected had ASD, kept a low profile, not asserting their needs. This resulted in misunderstandings and communication breakdown between service users and staff. A participatory research study by Nicolaidis et al., (2015) among 39 autistic adults, examining their experiences of healthcare, found that 'patient-level, autism-related factors,' for example; difficulties with communication and social skills, slow processing speed and sensory sensitivities impacted healthcare interactions.

Communication difficulties among the participants was further compounded by a lack of sensitivity or autism awareness on behalf of key workers. In the interviews with the three participants in our study, examples of positive engagement with service staff did not feature strongly. For Brian, this lack of sensitivity was perceived and described in strong terms. He believed that key workers were either unaware of or ignored his autism specific challenges and needs. Brian's experience/perception was of uncaring practitioners. A systematic literature review by Morris, Greenblatt & Saini (2019) concerning healthcare practitioner interventions and knowledge about ASD, revealed that service users with autism frequently experienced communication barriers with staff and that they perceived limited knowledge and skill of healthcare providers related to autism. This led to service users feeling unheard, stigmatized, and/or excluded from participation in assessment and treatment conversations.

Various research studies have identified homeless staff overwhelm (Casey, 2014), lack of confidence/competence Beer *et al.,* (2012) and inadequate training (Bruder, Kerins, & Mazzarella 2012). Campbell (2015) asserts that due to a lack of practitioner understanding concerning the characteristics and support needs of people with autism; expression of distress can be labelled as uncooperative, oppositional, or anti-social behaviour. In the study by Nicolaidis *et al.,* (2015), participants attributed many negative care experiences to practitioners' incorrect assumptions about the strengths and needs of people with ASD. These assumptions can lead to insensitive interventions that are experienced as uncaring or even abusive. Experiences of re-traumatisation in homeless services strongly featured in the narratives of Brian and Dezi particularly.

A respectful and supportive key working relationship was regarded as essential. Helpful approaches included appropriate and well judged 'pushing;' encouraging people to try out new experiences and take productive risk based on a sound knowledge of the strengths, needs and challenges of the individual (Clifford & Casey 2013). This 'pushing' was believed to be useful in countering the self-restriction and isolation that can accompany ASD. Arts and creativity were also seen as useful to extend comfort zones and facilitate self-expression/self-esteem (Clements-Cortez & Yip 2017).

Participants were keen to point out that people with ASD have special needs but do not need special treatment, just increased awareness, knowledge about issues and sensitivity to needs; an observation also made by Griffith *et al*., (2012).

3.3. Study 3: The self-perceived knowledge and skill levels among practitioners in homeless services regarding the characteristics, needs and support available/provided to people with autism.

This section details the findings from the 206 questionnaire responses. Not all respondents answered all questions therefore there is some variability in the response rates across questions; the response rate for each question is noted in the study findings. The questionnaire data was analysed using Qualtrics software. Content analysis was used for the open comment answers and the results for the three sections are outlined below.

3.3.1. Questionnaire part 1: Demographics, work context and training details

Respondents were asked a range of demographic questions; the responses are illustrated in Table 3.1. Overall, the demographic analysis revealed that respondents had varying lengths of service in homelessness, three quarters were female who had had little or no formal training in autism and identified as having low to average general knowledge about autism. Their exposure to autism mainly derived from service users and relatives/family members.

Table 3.1 Demographics, work context and training details

Age group	71% (n127) in the 25- 50 age group.
Sex (179 responses)	75% (n134) = female 24% (n43) = male 0.56% (n1) = other
Duration of work in homeless services (179 responses)	59% (n106) = under five years 41% (n73) = over 5 years
Work role (179 responses)	37% (n66) = project workers 30% (n54) = keyworkers 33% (n59) = variety of roles (case managers, managers, support workers, night support workers, specialist support).
Formal autism training/ education (179 responses)	85% (n153) = no formal training 15% (n26) = had formal training (short courses, applied behaviour analysis (ABA) training, undergraduate /postgraduate degrees in social work/care, nursing, education, psychology, child and family which included some coverage of autism).
Self-perceived knowledge of autism (175 responses)	26% (n45) low level of knowledge 65% (n113) average (layperson) level of knowledge 10% (n17) specialized knowledge of autism.
Know anyone in personal or working life with a diagnosis of autism.	• Client/service user = 38% (n76) • Other = 24% (n48) some did not specify but most identified a relative's/friend's child in this category • Close relative = 21% (n42) • Friend = 13% (n26) • Work colleague = 4% (n9) • Self-disclosure = 0.5% (n1),

3.3.2. Questionnaire part 2: Respondents knowledge and perceptions about autism

In defining autism, respondents were asked to finish the sentence 'Autism is…' making one selection. Answers are represented in table 3.2.

Table 3.2 Knowledge of Autism Spectrum Disorders

Answer	% (n)
A developmental disability	18% (n28)
A mental Illness	2% (n4)
An intellectual Disability	13% (n27)
A different way of interpreting the world and processing communication	67% (n140)
Total	100% (n209)

These answers reveal a good level of understanding of the nature of autism with 85% (n178) of respondents identifying neurodivergence and developmental difficulties. In terms of the national prevalence of autism, respondents estimated as follows in table 3.3.

Table 3.3 How common do you think autism is in Ireland today?

Answer	%
1 in 10 people	18% (n29)
1 in 100 people	40% (n65)
1 in 1000 people	23% (n37)
1 in 10,000 people	2% (n3)
Don't know	17% (n28)
Total	100% (n162)

As the correct figure is 1.5 in 100 people, 40% (n= 65) of the respondents answered this question correctly with 18% (n= 29) of respondents overestimating, 25% (n= 37) underestimating and 17% (n= 28) unaware of the prevalence of ASD in the general population.

Respondents were asked ‘What behaviours/characteristics might lead you to believe that a person may have autism.’ This was a question with an open comment box. In total there were 461 comments identifying 9 specific behaviours/characteristics. The results are as presented in order of citing frequency in table 3.4.

Table 3.4 Behaviours/characteristics perceived to be indicative of autism

Answer	%
Social interaction difficulties	28% (n127)
Set routines, fixations	19% (n88)
Difficulties with mental processing and development	15% (n69)
Sensitivity to stimuli	13% (n62)
Mental health and behaviour issues	13% (n59)
Above average intelligence	6% (n29)
Repetitive movements - tics flapping	5% (n23)
Vulnerable to extortion, bullying	0.6% (n3)
Risk of excessive substance use/addiction	0.2% (n1)
Total	100% (n461)

Not surprisingly, social interaction difficulties were identified as the most prevalent characteristic of autism. Being non-verbal was mentioned many times within these comments which raises the question as to whether respondents were considering individuals at the more severe end of the autism spectrum.

Other characteristics which featured strongly in the answers were; set routines/ fixations; difficulties with mental processing and development; sensitivity to stimuli and mental health and behaviour issues. The mental health/behavioural issues were virtually all attributed as result of frustration of communication/ processing. These identified characteristics would be consistent with prevalent ASD features cited in diagnostic and research literature. Interestingly, the vulnerability of people with ASD to extortion/bullying is only referred to in 3 comments and the risk of excessive substance use/addiction is mentioned once. However, one could argue that these are not characteristics specific to autism.

In relation to a question concerning perceived strengths of people with autism, there were 171 responses: 91% (n= 153) of respondents considered that people with autism had particular strengths, 0.58 % (n= 1) did not perceive particular strengths and 8% (n= 14) didn't know. A follow up open question asked respondents to identify strengths that they perceived in people with ASD. Many respondents detailed more than one perceived strength.

In total there were 170 comments identifying 4 specific perceived strengths. The results are as presented in order of citing frequency in table 3.5.

Table 3.5 Perceived strengths of people with ASD

Answer	**% (n)**
Above average intelligence. Good on facts based subjects with literal interpretation e.g. maths, technology etc.	61% (n104)
Unique way of looking at the world which we can learn from also artistic, creative, unique	24% (n41)
Honest	11% (n18)
Empathic, sensitive to others feelings, emotional intelligence	4% (n7)
Total	100% (n107)

The perceived higher intelligence level of people with ASD is the strongest feature in the responses, especially in relation to literal thinking. This high rating reflects a tendency among the public to overestimate the savant capacities of people with ASD. However, in contrast to the stereotype of the rigid, literal thinker who is emotionally detached; respondents also identified tangential/lateral thinking, creativity, honesty, empathy and emotional intelligence among the strengths of people with ASD.

The question ‘Do you think people with autism have particular difficulties?’ achieved 171 responses. Of these 94% (n= 161), considered people with autism to have difficulties, 2% (n= 3) believed they did not have difficulties and 4% (n = 7) did not know. A follow up open question asked respondents to identify particular difficulties that they perceived in people with ASD. Many respondents detailed more than one perceived difficulty. In total there were 270 comments identifying 8 specific perceived difficulties. The results are as presented in order of citing frequency in table 3.6.

Table 3.6 Perceived difficulties of people with ASD

Answer	%
Communication difficulties	35% (n95)
Social barriers (being misunderstood, not fitting in, stigma, lack of support)	23% (n63)
Processing and development issues (executive functioning) affecting abilities to cope	19% (n50)
Mental/emotional issues (emotional regulation, frustration anxiety, confusion, behavioural issues)	11% (n29)
Sensory issues and sensitivity to stimuli	10% (n27)
Rigid routines 'black and white' thinking	9% (n23)
Being bullied, being at risk/vulnerable	2% (n5)
Substance use	0.7% (n2)
Total	100% (n270)

Again, communication problems and processing/ development challenges of the person with ASD were most frequently cited as posing difficulties along with societal barriers. An additional recurrent finding is the low level of comments regarding the person with ASD being bullied or being at risk/vulnerable. Similarly, addiction has a low rating of being perceived as a difficulty with just two comments in this regard. Respondents were also asked to indicate to the best of their knowledge, the rates of co-existing cognitive/mental health features among people with ASD. The responses to this question are captured in table 3.7.

Table 3.7 Perceived rates of co-existing cognitive/mental health features among people with ASD

Question	None	Under 20%	20% - 50%	51% - 70%	Over 70%	Total
Intellectual Disability	3% (n4)	38% (n60)	41% (n64)	14% (n22)	4% (n7)	157
Mental Health Problems	2% (n3)	19% (n30)	47% (n73)	25% (n40)	7% (n11)	157
Substance Use	8% (n13)	51% (n80)	32% (n50)	8% (n12)	1% (n1)	156
Behaviours that challenge	1% (n1)	8% (n13)	27% (n43)	45% (n72)	19% (n30)	159
Special ability eg: Maths, Music, Art	1% (n1)	11% (n18)	31% (n49)	37% (n58)	20% (n32)	158

Respondents' knowledge was seen to be lacking concerning common ASD comorbidities and characteristics. Comorbidities and challenges tended to be under-estimated, for example, prevalence of intellectual disability (ID) and mental health problems, as compared to prevalence statistics and current research. Substance abuse among people with ASD received little recognition among respondents both in direct questions and free comment sections. Features that respondents perceived as commonly occurring with ASD were behaviours that challenge and the presence of special abilities/talents

3.3.3. Questionnaire Part 3: Autism and homelessness

This was an important section in the questionnaire, which aimed to gather perceptions of service provision for people with ASD and support for practitioners working with homelessness and autism. Respondents were asked to estimate the prevalence of autism among people who are homeless in Ireland. The subsequent findings are displayed in table 3.8.

Table 3.8 Estimated prevalence of co-occurring autism and homelessness

Answer	% (n)
0% - 10%	17% (n26)
11% - 20%	27% (n41)
21% - 30%	20% (n30)
31% - 40%	10% (n15)
41% - 50%	4% (n6)
51% - 60%	2% (n3)
61%+	1% (n1)
Don't know / Would prefer not to estimate	20% (n30)
Total	100% (n152)

There is little research concerning prevalence of autism among homeless populations. Churchard et al., 2019 estimated this figure to be 12% as opposed to 1.5% of the housed population (Boilson et al., 2016). In this questionnaire, over half the respondents considered the prevalence of ASD among homeless populations to be between 11% and 40%. This is quite a high estimation of ASD prevalence rate among homeless people particularly in comparison to the respondents' earlier estimates of autism among the general population, which was perceived by only 18% of respondents to be over 10%. Respondents were asked for their perceptions regarding people with ASD and homeless pathways. Their perceptions are summarised in table 3.9.

Table 3.9 Perceptions regarding people with ASD and homeless pathways

Question	Strongly agree/agree	Neither agree nor disagree	Strongly Disagree/ Disagree	Total
People with autism are more likely to be homeless than people without autism	25% (n38)	42% (n64)	33% (n49)	151
People with autism need special consideration when it comes to housing allocation	81% (n123)	13% (n20)	5% (n8)	151
People with autism find it more difficult to exit homelessness than people without autism	61% (n92)	30% (45)	10% (n14)	151

Many respondents perceived that people with ASD find it more difficult to exit homelessness that people without ASD and the majority of respondents believed that people with ASD needed special consideration in housing allocation. Respondents were asked what might affect people with ASD achieving and maintaining a suitable home. This was an open comment question achieving 215 comments identifying a range of perceived challenges. The results are as presented in order of frequency in Table 3.10.

Table 3.10 Perceived challenges for people with ASD achieving/maintaining a home

Answer	%
Processing and executive functioning – navigating systems, bureaucracy, tenancy arrangements, paying bills and rent, managing community resources, activities of daily living (keeping self/home clean and tidy, cooking, shopping).	36% (n78)
Societal and support issues – lack of appropriate services and sensitive placements, lack of public/service understanding of people with ASD, stigma, vulnerability to abuse, lack of staff training, lack of ongoing/ maintenance support	33% (n72)
Communication difficulties - interacting with landlords and neighbours, managing viewings, self-advocacy, community engagement	21% (n45)
Mental health issues, emotional regulation, challenging behaviour	5% (n11)
Rigid routines	2% (n5)
Sensory overload	2% (n4)
Total	100% (n215)

Interestingly, processing and executive function is now perceived as the biggest challenge, followed by societal and support issues. Communication difficulties does not receive the same level of importance as in section 2 of the questionnaire. A key question related to respondents' perceptions of their own skills and knowledge when supporting people with ASD. This was assessed using a Likert scale of ten items pertaining to this area. Responses are illustrated in Table 3.11.

Table 3.11 Perceived level of skills and knowledge in supporting people with ASD in homeless services

Question	Strongly agree/agree	Neither agree nor disagree	Strongly disagree/ disagree	Total
I feel confident about identifying autistic behaviours as part of client assessment	44% (n66)	27% (n40)	29% (n44)	150
If I identify autistic behaviours in a client who does not have an autism diagnosis, I would know what action to take next	40% (n59)	17% (n25)	44% (n64)	149
I feel that I have enough knowledge about the specific needs of autistic people to be able to work effectively with them in my service	33% (n49)	17% (n25)	51% (n75)	149

Question	Strongly agree/agree	Neither agree nor disagree	Strongly disagree/ disagree	Total
I need to make my communication more sensitive to the needs of people with autism	71% (n105)	22% (n33)	8% (n11)	149
I am satisfied with the training that I have received regarding working with autistic people in my service	6% (n8)	16% (n24)	78% (n116)	148
I have received little or no formal training specifically related to autism	69% (n103)	8% (n12)	24% (n35)	150
I learned most of what I know about autism through personal experience	66% (n98)	15% (n22)	20% (n29)	149
I learned most of what I know about autism through professional working experience	45% (n67)	18% (n27)	37% (n55)	149
I am aware of services and supports that I can avail of/refer clients to for autism support	34% (n51)	16% (n24)	50% (n74)	149
I would like to avail of training specifically related to understanding and supporting the needs of autistic people in homeless contexts	94% (n140)	5% (n7)	2% (n2)	149

Less than half of the respondents were confident in their ability to identify autistic behaviours as part of client assessment. Upon identifying autistic behaviours in a client who did not have an ASD diagnosis 60% of respondents were either not sure or did not know what action to take next, or where they could access autism support services.

Almost three quarters of the sample were either not sure of their level of knowledge or felt that they did not have enough knowledge to work effectively with people with ASD; these deficits mainly centred on communication skills Many respondents identified their ASD knowledge as coming from personal or professional acquaintance with people with ASD. Most expressed dissatisfaction with ASD training they had received to date and 94% would like to avail of training specifically related to understanding and supporting the needs of autistic people in homeless contexts.

Responding to a further question, 43% (n= 65) of respondents identified that they found aspects of working with people with ASD challenging, 17% (n= 25) perceived that working with autistic service users was not challenging and 40% (n= 61) didn't know whether aspects were challenging or not. There would appear to be a lack of clarity/consensus among respondents in this regard. Among the 43% who identified challenging aspects, the following were noted from 140 comments regarding specific areas in Table 3.12.

Table 3.12 Challenges encountered by participants in supporting service users with ASD

Answer	**% (n)**
Not trained regarding appropriate and sensitive assessment and support planning for people with ASD. Difficulty in understanding needs of people with ASD	49% (n68)
Lack of diagnostic service or dedicated support for adults with ASD. Lack of knowledge where to refer, inappropriate services. Feel they are 'winging it'	24% (n34)
Communication – want specialised skills, not confident establishing rapport, finding time to get to know person in a chaotic environment	14% (n20)
Working with challenging behaviour/emotional difficulties and self-harm. Identifying and preventing/working with triggers	9% (n13)
Helping with processing difficulties, improving engagement and rapport, helping people to understand complexities and bureaucracy.	4% (n5)
Total	100% (n140)

Many of the challenges identified in this area appear to be related to respondents' perceived lack of training and the lack of appropriate service provision for people with ASD

3.3.4. Perceived level of support for people with ASD in homeless services

In terms of perceived level of support for people with ASD in homeless services, 92% (n= 132) of respondents reported that there were no specific interventions or arrangements for people with autism within their services. The 8% (n= 12) who identified the presence of autism specific interventions/arrangements defined these as quiet rooms, respect for clients' wishes for minimal social interaction, awareness of triggers, sensitive approach. Further, when asked for opinions as to whether homeless services in Ireland provide adequate provision for people with ASD, 72% (n =109) of respondents responded No; 4% (n= 6) responded Yes and 24% (n = 36) didn't know. The free comments follow up to this question asked how homeless services for people with ASD could be improved. The following recommendations were made (n= 110 comments) in Table 3.13.

Table 3.13 Suggested improvements for people with ASD in homeless services

Answer	%
Staff training (on assessment of needs, care planning/interventions, existence and nature of appropriate services)	49% (n54)
Specialized housing services for ASD required - not adequate provision in homeless services. Special team, for people with ASD who need extra support. People with ASD should be prioritised for housing with strong interagency support	31% (n34)
Autism friendly environment within homeless services; bigger rooms, non-shared, not mixed in with chaotic homeless clients and drug users, sensory gardens etc	20% (n22)
Total	100% (n110)

Respondents focused on infrastructure, service provision and training in this answer, there were few comments concerning ASD specific treatment/ support approaches or trauma informed care. Finally, respondents were asked about their perceptions regarding the need for and nature of training. Answers are illustrated in Table 3.14.

Table 3.14 Perceptions regarding the need for and nature of ASD training

Question	**Strongly agree/agree**	**Neither agree nor disagree**	**Strongly disagree/ disagree**	**Total**
Training is not required; general sensitivity to the needs of homeless clients is enough	4% (n5)	5% (n7)	92% (n128)	140
Training should be mandatory	80% (n112)	16% (n23)	4% (n6)	141
It should be small group training	73% (n101)	24% (n33)	4% (n5)	139
Training should be online	17% (n23)	37% (n52)	46% (n65)	140
Training should be in lecture format	34% (n48)	42% (n58)	24% (n33)	139
All information required could be contained in a guidebook	41% (n57)	32% (n45)	27% (n38)	140

Most respondents identified that training was required and that this should be mandatory. In relation to the nature of training, small group format was most popular; almost half the respondents felt that a guidebook would be useful; lecture format was less popular, and online delivery was not particularly favoured. A recommendation was made to include people with lived experience of homeless and autism in planning and delivery of training.

3.3.5. Discussion of Study 3

Practitioner knowledge regarding ASD

The findings of this study show that despite 38% of respondents identifying a service user/client as their primary acquaintance with autism, 85% of respondents had had little or no formal training in autism and largely identified themselves as having 'layperson' level of knowledge regarding the features of autism. This level of knowledge was confirmed in the questionnaire responses for example regarding the features of autism. The respondents were highly cognisant of the challenges and difficulties for people with ASD in relation to communication/interactional skills, processing and interpretation. However, less respondent knowledge was apparent concerning the psychosocial challenges experienced by people with ASD and specific helpful approaches to supporting people with ASD.

Co-existing difficulties such as intellectual disability and mental health problems was underestimated in comparison to population prevalence figures for these conditions (NDA, 2017; Buck et al., 2014; Iemmi, Knapp, & Ragan (2017)

There was little reference to ACE or trauma as a feature or challenge in the lives of people with ASD, although these issues have been identified as prevalent by Sizoo et al., (2010) and Butwicka et al., (2017). The findings also revealed that keyworker respondents underestimated the level of substance abuse among people with ASD. As previously highlighted, rising prevalence and under diagnosis of substance use among people with ASD are increasingly evidenced in research, (Lundström et al., 2011; Butwicka et al., 2017). It was formerly believed that the common features of autism, i.e. social withdrawal and risk aversion were protective factors against substance abuse (Rothwell, 2016). Sizoo et al., (2010) also point to this assumption influencing the lack of substance use screening among the ASD population. This belief may account for the under estimation among study respondents.

Respondents identified societal challenges for people with ASD in terms of not fitting in, stigma and inadequate service provision. However, they underrepresented the level of risk of extortion, victimisation and bullying which is evident in the literature in this regard (Lougheed & Farrell, 2013; and Forrest, Kroeger and Stroope, 2020). Bishop-Fitzpatrick et al., (2019) argued that social work literature does not pay sufficient attention to identifying causes and consequences of marginalisation among people with ASD nor does it provide enough guidance on developing sensitive, effective interventions for people with ASD. Primary, secondary and tertiary health promotion, originally conceptualised by Leavell & Clark (1953) is a commonly used framework which is relevant here. Government agencies, local services and social care practitioners have a fundamental role in preventing people with ASD from developing co-morbidities/becoming homeless in the first instance through effective screening and support (primary prevention). Secondary prevention involves crisis management and cross disciplinary work with people with ASD and their support networks when there is a risk of homelessness. Tertiary prevention, through the provision of intensive interagency support, works to achieve early exit from homelessness and prevent entrenchment and the development of attendant issues such as addiction, offending behaviour and mental health problems.

In terms of strengths, perceptions of high intelligence and special abilities were possibly overrepresented in the responses. As previously outlined, studies concerning the presence of high intelligence and special abilities in autism vary in their prevalence rates. Draaisma (2009) argued that there is a public stereotype that all people with autism have savant abilities and this overestimation would appear evident in the findings of this survey. Respondents also perceived characteristics of honesty, lateral thinking, creativity, empathy, and emotional intelligence among people with ASD. These strengths have also been identified by [redacted] (2015).

Behaviours that challenge were widely considered by the respondents to be a commonly occurring feature of adult autism. However, in later sections of the questionnaire, this was not frequently cited as an issue that practitioners struggled with. It was not clear from the findings, whether the respondents' estimation of behaviours that challenge was based on common ASD stereotypes, or to what extent respondents had encountered this behaviour among people with ASD in their practice. Behaviours that challenge among children with ASD have an estimated prevalence from 56% to 94% (Matson & Nebel-Schwalm 2007) chiefly due to the characteristics and frustrations of autism, however these behaviours appear to decrease in adulthood (Shattuck, Roux & Hudson, 2012; Matson et al., 2011).

Respondent estimation of ASD prevalence rates, perceptions of ASD challenges and support among people who are homeless

There was a high estimation of ASD prevalence rate among the homeless population; half of the respondents estimated this figure as between 11% and 40%. This figure is supported by the ASD prevalence rate of 12% found by Churchard et al., (2019), especially when the cases of suspected autism in that study are taken into account (20%). This respondent prevalence estimate is also in accord with the earlier questionnaire response wherein 38% of these practitioners indicated that they had encountered people with ASD as service users/clients. This respondent estimate is much higher than the estimated prevalence of ASD among Irish homeless in study 1, however it is not clear whether respondents are considering a much wider profile of homeless persons, including rough sleepers/street homeless in their estimates as opposed to the relatively stable homeless population researched in study 1.

Many respondents perceived that people with ASD find it more difficult to exit homelessness than people without ASD and that people with ASD need special consideration in housing allocation. These findings are in accord with research by Backer and Howard (2007) and Canavan (2018). In relation to the challenges for people with ASD achieving/maintaining a home, processing and executive function skills were perceived as the biggest challenge (also highlighted by Churchard et al., 2019), followed by societal and support issues (NAS, 2017; NDA, 2017). Although respondents recognised these challenges for people with ASD, they also perceived that the level of support in homeless services was poor; the majority of respondents, who represented a range of Irish homeless services, reported that there were no specific interventions or arrangements for people with autism within their services. The small number of respondents who identified the presence of autism specific interventions/arrangements in their services, defined these as quiet rooms, respect for clients' wishes for minimal social interaction, awareness of triggers and sensitive approach. These ASD service responses appear vague and are focused on giving space rather than on active engagement. Further, respondents considered that provision for people with ASD in Irish homeless services generally was inadequate, a finding supported by recent Irish research and reports (NAS, 2017; NDA, 2017; Canavan, 2018).

Respondents' self-evaluation of skills, knowledge and training needs for working with people with ASD in homeless services

The self-evaluation of skills and knowledge in working with people with ASD in homeless services was low, particularly in relation to ASD assessment skills, addressing service user needs, using ASD sensitive communication approaches and locating and involving appropriate ASD support. Research identifies that staff working in homeless services often feel overwhelmed with competing demands and complex caseloads (McLaughlin, Casey & McMahon, 2019; Casey, 2014) and that they struggle to address the specific needs of clients with ASD (Beer et al., 2012). A systematic review by Morris, Greenblatt & Saini (2019) referred to the 'well-documented lack of autism relevant knowledge and skills training among healthcare professionals across disciplines' and reported that limitations in knowledge and skills training of health professionals have been identified by people with ASD as resulting in unmet healthcare needs.

Similarly, the practitioner respondents in our study saw their practice limitations as related to their perceived lack of training and the lack of appropriate service provision for people with ASD. A significant number of respondents were not satisfied with the level of formal training that they had received regarding ASD among homeless service users; a finding supported by other research studies in this regard (Bruder, Kerins, & Mazzarella 2012; Kuhlthau et al., 2015). Many respondents indicated that they had learned most of what they knew about autism primarily from personal experiences and also professional/work related experience.

The majority of respondents expressed the desire to avail of training specific to the needs of people with ASD with a preference for a small group interactional delivery model involving people with lived experience of ASD and homelessness in the planning and delivery of training.

Section 4 – Triangulation and discussion of findings

Triangulation of findings was achieved by extracting the common elements and themes across the three studies. These common findings were analysed in relation to how they manifested in each study and whether they held true across studies. These triangulation results are described in table 4.1 below.

Table 4.1 Summary of triangulation across the three studies

Findings	Study 1: Prevalence	Study 2: Clients with ASD	Study 3: Keyworker knowledge
Prevalence	One hundred and six individuals were screened, of these 3 individuals (2 males and 1 female) screened "present" for autistic traits on the DATHI screening questionnaire, giving a prevalence estimate of 2.8% (95% CI: 1% - 8%). A further 7 clients obtained "possibly present" scores, providing a combined prevalence estimate of 9.4% (95% CI: 5% - 16%) amongst the population screened.	Both Jozef and Dezi referred to knowing people with ASD in homelessness, many undiagnosed. Dezi worried about young people on the boardwalk that may have ASD.	Keyworker respondent estimates of people with ASD in general population was reasonably accurate Estimates of people with ASD in Irish homeless services, from keyworker estimate was high.
Diagnosis	All clients identified by key workers (n =3 present and n=7 possibly present) were suspected of autism spectrum disorder. None had been formally diagnosed	Dezi (66) and Jozef (42) were not formally diagnosed and felt this was detrimental to their development and self-understanding. Brian (27) formally diagnosed at 6	Respondents identified a lack of awareness concerning autism services and in getting an ASD assessment for clients. They see this as detrimental to the care and support of people with ASD in homelessness.

Findings	**Study 1: Prevalence**	**Study 2: Clients with ASD**	**Study 3: Keyworker knowledge**
Knowledge of autism	Key workers demonstrated good level of knowledge traits, while completing the DATHI screening	Participants with ASD gained knowledge through personal efforts reading about ASD, self-observation. High level of insight regarding ASD features	Respondents gained knowledge through personal and professional exposure. Laypersons level. Good level of knowledge re traits. Knowledge gaps particularly around specific issues and interventions. Little formal training in autism.
Adverse childhood experiences /trauma	53% of the general sample had a history of traumatic events (diagnosed /suspected). No significant difference in the present or possibly present group.	All 3 participants described ACE/trauma in addition to autism, domestic violence, family mental health issues, rejection, neglect	Little identification of ACE/trauma in key worker responses
Bullying and abuse (outside family)	Psychological abuse and bullying from others (current 16%, past 10%) of the general sample. Violence & Aggression from others (current 18%, past 10%) of the general sample	All 3 participants described incidents of bullying abuse (including perceptions of abuse by homeless services in 2 cases). Childhood bullying caused lifelong damage	Little identification of bullying or abuse/extortion as a consideration/risk in key worker responses (compared to high rate in literature/stats)

Findings	**Study 1: Prevalence**	**Study 2: Clients with ASD**	**Study 3: Keyworker knowledge**
Concurrent mental health morbidities	History of mental health problems 73% of the general sample (diagnosed / suspected). The entire present or possibly present sample (n=7) had history of mental health problems (diagnosed / suspected). Depression, anxiety disorder and psychosis (schizophrenia) most prevalent diagnosis.	Participants described low mood, anxiety and fear but no specific diagnosis	Key workers under-estimated the prevalence of mental health comorbidity (compared to research literature/stats)
Addiction	41% among general sample had a history of drug and alcohol abuse. 1 person from the possibly present sample (n=4) had a history of addiction	All 3 participants had past alcohol addiction. 1 person had past gambling addiction	Key workers largely under-estimated the prevalence and risks of addiction among this population (compared to stats)

Findings	**Study 1: Prevalence**	**Study 2: Clients with ASD**	**Study 3: Keyworker knowledge**
Service Utilization/ Experience	Majority of clients registered with GP 94% engaging in drug and alcohol services 41% community mental health teams 22%. No significant differences observed present/possibly present as related to use of homeless services.	Varied experiences but all perceived a lack of understanding of their needs. Difficulty in access. Stigma, Inappropriate placements. Perception of lack of care/indifference from staff	Practitioners identified their own lack of training and support. Common perception that their own and national homeless services were not catering adequately for the needs of people with ASD
Communication and interventions	N/A	Difficulties because of own processing and interpretation issues which was complicated by lack of understanding/ sensitivity/ empathy from staff. Ableism, inappropriate expectations. Strong relationship with a keyworker who took time seen as essential. Gentle pushing and activities to productively extend comfort zones seen as useful	High level of participants indicated that they needed to improve their communication/ intervention skills with people with ASD and cited lack of knowledge, time and support.

Findings	**Study 1: Prevalence**	**Study 2: Clients with ASD**	**Study 3: Keyworker knowledge**
Addiction treatment	N/A	All 3 participants overcame their addictions. Group therapy was challenging in the context of ASD and not seen as helpful. Personal motivation and willingness to expose self to therapeutic challenges helped.	N/A

Recommendations	Development of research and evidence base, enhance awareness and training, improve service diagnostics and supports for adults on the autism spectrum. Development of cross disciplinary models of support, continuous training of public service workers and medical professionals related to autism spectrum disorders. Clear pathways to diagnosis and service provision for adults with ASD through appropriate referral pathways. Improved diagnosis and support for those with ASD and comorbidities	Improvements in childhood and adult diagnosis. Help and support in understanding self in context of ASD. Better access to supportive homeless services Improve ASD understanding and sensitivity from staff particularly in relation to communication and expectations, trauma informed care. Greater appreciation of the difficulties for people with ASD in engaging in group based interventions (i.e. addiction approaches) Appreciation of vulnerabilities and strengths. Building a strong therapeutic relationship based on knowledge and understanding of person. Gentle encouragement to extend skills and abilities and take	Development of screening and diagnosis – practitioner training/basic tools to be used for screening for autism. Development of appropriate diagnostic tools and support for adults with ASD – homeless practitioners made aware of these Greater level of support for people with ASD in homeless services; autism friendly environments, practitioner training in working with people with ASD. Increase practitioner awareness knowledge and skills regarding ACE, trauma and trauma informed care Specialist team to support adult diagnosis, fast tracked housing and ongoing

Findings	Study 1: Prevalence	Study 2: Clients with ASD	Study 3: Keyworker knowledge
		on new experiences.	support for people with ASD. Large consensus on the need for ASD training for practitioners in homeless services. Should be mandatory Small group discursive type training, toolkits preferred

4.1. Discussion of triangulation of findings

4.1.1. Prevalence of autistic traits in a sample Irish homeless population

From a sample of 106, derived from a large Dublin homeless service, 3 individuals (2 males and 1 female) screened "present" for autistic traits, giving a prevalence estimate of 2.8%. A further 7 clients obtained "possibly present" scores, providing a combined estimated prevalence estimate of 9.4%. This prevalence estimate is considerably lower than the estimate reported in the UK study by Churchard et al., (2019) in which the present estimate was 12% and the combined prevalence estimate of present and possibly present was closer to 20%.

The differential in the Irish/UK estimate is likely to relate to the composition or profile of the sample across the two regions; the UK sample had a longer homeless duration and a higher rate of entrenched homelessness and rough sleeping, this indicates that individuals in the UK sample may have been more vulnerable with possible greater mental health and underlying neurodevelopmental problems.

People with ASD who find that they cannot cope with the many environmental, relational, and structural aspects of homeless services (as highlighted in our research) are less likely to engage with services and are more likely to sleep rough (Evans, 2011; Campbell 2015; Kargas et al., 2019). The sample in the Irish study had shorter homeless trajectories and were able to engage with homeless service provision. This could also mean that the severity of their autism traits was not as extreme or that they were able to modify or camouflage traits in order to 'fit in' or avail of services (Jones et al., 2014; [redacted] 2016). In this scenario, the ASD traits may not have been as obvious to key workers when they were completing the DATHI. In study 2 both Jozef & Dezi referred to knowing people with ASD in homelessness, many undiagnosed. Most of the people they referred to were tenuously housed or sleeping rough. In study 3, respondent estimates of people with ASD in the Irish homeless population was high but it is not clear whether respondents were referring to rough sleepers or people with ASD who were engaged with services. Therefore, this Irish prevalence estimate of ASD among people who routinely engage with homeless services serves as a useful extension of previous ASD in homelessness research.

4.1.2. Screening, diagnosis and self-knowledge of autism

It is well documented that autism prevalence estimation is an extremely challenging task for the scientific community, even in a 'stable' population. People with autism are a hard to reach population - this is well described and evidenced in a recent study (DCU Autism Friendly University Project). [12]

The major challenges in screening and diagnosis among homeless people with ASD was a prominent feature in all three studies. None of the present or possibly present cases in study 1 had received a formal diagnosis of ASD. Only one of the three participants in study 2 was formally diagnosed and this lack of diagnosis caused distress. The key workers in study 3 identified lack of diagnosis services as hampering their work in supporting people with ASD in homeless contexts.

Knowledge about autism came slowly for the participants in study 2. Although Brian had been diagnosed at age 6, he did not have the opportunity to make sense of his behaviours and feelings of alienation until his twenties, similarly Jozef and Dezi are still reflecting on what ASD means for them. Studies by Jones et al., (2014) and Camm-Crosbie et al., (2019) highlighted how experiences and perceptions of autism recognition and acceptance influenced the mental health of autistic adults. Autism acceptance from external sources and personal acceptance significantly predicted the likelihood of depression and reported that there was a strong correlation between early diagnosis and satisfaction at school amongst people with high-functioning ASD. Early diagnosis and support of ASD constitutes a strong method of primary prevention of homelessness amongst this cohort.

Practitioners play a key role in helping individuals to process diagnosis and life experiences, and although the practitioners in studies 1 and 3 had a good level of knowledge about autism traits, there appeared to be knowledge deficits concerning co-morbidities, psychosocial issues and helpful interventions for people with ASD in homelessness. These deficits were highlighted by both the service user and practitioner participants in studies 2 and 3. The requirement for early diagnosis is foregrounded in our research; however, there are many challenges in achieving a diagnosis for people with ASD. The primary barriers are a lack of research on ASD diagnostic tools and scarcity of resources and ASD screening services for adults in Ireland and elsewhere (Canavan 2018). The pressure on services would be alleviated if valid tools were available for making a reliable first evaluation on which to base the decision of whether to proceed with time-consuming and expensive assessment procedures (McKenzie et al 2019).

Walęcka, Wojciechowska, & Wichniak (2020) assert that ASD in adults can be difficult to differentiate from other mental disorders and that many adults with ASD are misdiagnosed. As can be seen from our research, there is a high level of mental distress among all

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[12] http://doras.dcu.ie/view/people/Sweeney=3AMary_Rose=3A=3A.html

participants and these comorbidities make an autism diagnosis challenging. Autistic people who are homeless, (especially if they are rough sleeping) are unlikely to engage in prevalence screening due to a range of social and personal factors already described in the introductory section of this report. Indeed, they may not be aware that autism exists as a condition or be aware of the characteristics as pertaining to themselves. Walęcka, Wojciechowska, & Wichniak (2020) also argue that most of the available screening and diagnostic tools rely on self-reporting; this demands a level of self-awareness and introspection that may not be present among some people with ASD. Mental health and cognitive processing issues may hinder accurate self-representation. For adults, the quality of informant's recall might not be detailed or reliable due to the long time elapsed from subject's childhood to the current assessment (Lai & Baron-Cohen 2015). Alternatively, individuals with high cognitive abilities may have developed camouflaging or compensating strategies during their childhood, thus being able to mask the core ASD symptoms in order to 'fit in' with neurotypical populations (Jones et al., 2014; Fusar-Poli *et al*., 2017).

Sizoo et al., (2015) examined three self-reporting ASD measures, RAADS-R, AQ-28, AQ-10 and concluded that both the sensitivity and specificity of each of these instruments was insufficient and that none of these instruments had sufficient predictive validity to be used to predict clinical outcome in out-patient settings. Additionally, studies by Baghdadli, Russet, & Mottron (2017) and Hirota et al (2018) highlight the limited evidence for the efficacy of a range of ASD screening tools among adults.

Churchard et al., (2019) assert that the ideal process of determining prevalence of autism in adults is to combine results from standardised self-report, direct observation and informant-report measures to gain a picture of current behaviour and developmental history. However, these researchers also identify that the challenges described above led them to adopt an informant report/ proxy measure of estimating prevalence traits. This methodology, already described, also formed the basis of the Irish prevalence study. Reviews of the validity and utility of informant reports and proxy tools vary in the literature. Benítez Baena et al., (2012) evaluated the convergence between self-reporters and informant reporters in a disability questionnaire using a behaviour coding method and finding a high correlation between both types of informant, concluded that proxies could be considered at least as good informants as self-reporters. However, a study Oosterveld-Vlug et al., (2015) regarding informant reports of dignity among residents in nursing homes found that informant reliability was at its highest when the resident behaviour was observable and

that if research participants are not able to provide information themselves, there can still be value in proxy responses. In relation to self-report and informant report comparisons in ASD, many studies acknowledge that multi-informant methods are the gold standard, however there appears to be agreement on a satisfactory convergence of self and informant reports (Moss et al 2015; Sandercock et al 2020). Similarly Churchard et al., (2019) undertook rigorous testing of the proxy DATHI tool before use.

4.1.3. ACE, trauma, victimisation and abuse.

Studies 1 and 2 showed strong prevalence of trauma among participants both within their original family homes and in their subsequent school and social environments. The evidence base and nature of these issues among people with ASD has already been discussed in earlier discussion sections. (Peterson et al., 2019; Ressel et al., 2020: Forrest, Kroeger &

Stroope 2020). The correlation between adverse childhood experiences or trauma among people with ASD is under-researched (2018). Similarly, in the key worker identification of challenges and needs in study 3, ACE, trauma and bullying did not feature very strongly. Trauma informed care (TIC) practices have become more prevalent in homeless services in recent years, however these approaches are still largely viewed as most suitable for those who have experienced/disclosed childhood abuse, gender based violence and among those who have mental health issues (Prestidge, 2014; Deck & Platt, 2015; Milaney et al; 2020). Kerns, Newschaffer, & Berkowitz (2015) highlight that practitioners do not commonly associate autism with trauma and therefore appropriate screening and TIC may not be employed. People with autism may not verbally articulate or disclose trauma and signals of trauma may be missed by practitioners who may interpret these as ‘typical’ autism traits and behaviours such as stimming and behaviours that challenge.

As is evident in this study, respondents’ recommendations focused on infrastructure, service provision and training with no recommendations concerning specific interventions or approaches that might be helpful for people with ASD. The lack of recommendations in this regard also reflects the lack of knowledge regarding the needs of people with ASD identified by both the practitioner respondents and the service user participants in study 2.

4.1.4. Concurrent mental health and addiction issues

As previously highlighted and discussed, mental health issues and addiction are increasingly recognised as potential co-morbidities in people with ASD. This propensity was evident in study 1 where all present or possibly present cases were identified as having comorbid mental health issues and one person identified as having recent substance use issues. In study 2 the participants did not indicate that they had received a mental health diagnosis yet all three participants experienced intense levels of mental distress and all three had developed addictions as a consequence of attempting to alleviate ASD related difficulties and mental pain. Respondents in study 3 identified mental health issues and addiction as potential challenges, however these difficulties were underestimated and there was little sense of practitioner knowledge or experience of ASD related assessment or support planning in the context of co-morbidity.

4.1.5. Service provision for homelessness and co-morbidities

Like Jozef in study 2, Griffith et al., (2012) found that adults with high-functioning autism desired flexible support, as their needs fluctuated in response to life-events and over time. In study 1 most clients from the generic sample were reported as registered with a GP, almost half were engaged with addiction services and almost one quarter engaged with mental health teams. Participants with ASD in study 2 however, identified the difficulties in accessing appropriate homeless services in the first instance and often continued difficulties regarding the fit of the service to their ASD specific needs. Participants in studies 2 and 3 also highlighted the lack of autism friendly facilities in homeless services. These deficits have been widely signalled in research literature (Nicolaidis et al., 2015; Raymaker et al., 2017). There is an urgent requirement to address this underdeveloped area given that it is the source of much distress for service users and contributes to poor engagement in care.

The perennial issue of poor management of comorbidities or dual diagnosis (mental health issues and addiction; ASD and mental health issues: ASD and addiction) is frequently cited in literature. For example, there are few clinical guidelines as to how people with ASD should be assessed and treated for co-occurring addictions.

The UK's National Institute for Health and Care Excellence (NICE, 2011) [13] provides guidance on treatments for alcohol-use disorder but overlooks people with co-occurring intellectual disability and autism. Similarly, the NICE guidelines for diagnosis and management of ASD in adults (2016) [14] includes guidelines for co-existing mental health issues but not addiction. This means that accessing substance use services and benefitting from appropriate treatment is difficult for people with ASD. The participants in study 2 identified the use of group work and inappropriate placements as not sensitive to their ASD needs in addiction treatment. Drake (2018) identified that it took 18 months to find a workable strategy that addressed a person's alcoholism in the context of ASD and intellectual disability and concluded that the combined challenges of alcoholism, autism and intellectual disability are poorly understood and under researched.

4.1.6. Specialised and mainstreaming approaches

The call from respondents in study 3 for specialised services for people with ASD is interesting and one that is echoed in research literature and recent NDA reports (NDA, 2017). In the context of this study, respondents identified specialised services as a specialist team to support adult diagnosis, fast tracked housing and ongoing support for people with ASD. The perceived requirement for specialist homeless services may also reflect the respondents' lack of confidence in working effectively with this population and the desire to ensure that people with ASD receive the best care. This may contrast with what Jozef recommended in Study 2; that people with ASD do not want special treatment but rather to enjoy a greater level of understanding of their strengths and needs among all practitioners. Brown (2018) voices a similar perspective in recommending joint, interdisciplinary working wherein a range of practitioners from different services; addiction services, intellectual disability/ASD services, homeless services and mental health services can share knowledge and evidence based interventions in the support of people with ASD. This also reflects the mainstreaming approach supported by Irish policy and strategy. However, it is also evident that specialist services would be valuable, particularly in relation to dual diagnosis and comorbidities.

4.1.7. Training and knowledge

Practitioners in study 3 identified their own lack of training and their perceptions that their own and national services were not catering adequately for those with ASD. Interestingly, participants in study 2 acknowledged their own communication challenges as interfering with productive staff relationships but were also able to recognise limitations in staff. This lack of understanding had a negative effect on participants in study 2 who perceived practitioners as incompetent, indifferent, or uncaring. Practitioners in study 3 also realised that they needed to improve their sensitivity and communication skills among people with ASD but felt that they needed training for this to develop. The dearth of training and the ensuing impact on practitioners and service users has already been discussed and this call

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[13] https://www.nice.org.uk/guidance/cg115

[14] https://www.nice.org.uk/guidance/cg142

has been widely made across a range of research literature. This is one of the strongest findings and recommendations of the study. It is envisaged that with greater understanding of the needs of this population, practitioners will be better able to assess and address their specific needs in practice and will advocate for the necessary changes in social care systems, policy and strategy.

Section 5 - Conclusion, Strengths, Limitations and Recommendations

5.1. Conclusion

This comprehensive research project used a range of research methods to estimate the prevalence of autistic traits and the lived experiences of those experiencing ASD in homeless contexts. In addition, the knowledge level, service perceptions and training needs of homeless practitioners were explored. Findings and discussion from the three individual studies provide depth and clarity to a range of underexplored areas. The triangulation of findings crystallises and condenses the important messages from the research which can be used to advance understanding, develop knowledge and practice as well as inform government policy and strategy regarding autism and homelessness.

5.2. Strengths

This novel research has a number of strengths. Study 1 provides new research evidence concerning estimated ASD prevalence rates among homeless populations who are engaged with homeless services. Previous studies have examined estimated high ASD prevalence among entrenched homeless/ rough sleepers who have complex co-morbidities and who are often not engaged with homeless services. The current research, with its focus on a population less entrenched in homelessness, expanded the population screened using the DATHI tool and confirmed that the estimated prevalence of homelessness was less than among a more entrenched cohort. However, the ASD prevalence estimate among the service-engaged clients was still in excess of that of the general population.

Study 2 provided rare and often poignant insights into the circumstances, struggles and strengths of people with autism in homelessness and enabled their voices to be central to the study. Study 3 surveyed a wide range of homeless practitioner knowledge and opinions as to how their own practice and that of homeless services in Ireland need to develop in relation to the care of people with ASD. Again, this level of specificity is novel and constitutes a strong contribution to research literature.

5.3. Limitations

Across the three studies, the onset and effects of COVID-19 had a serious impact, particularly in terms of participant/respondent recruitment and ongoing availability/commitment to the research inquiry. The research team and our research partners worked tirelessly to adopt creative and flexible workarounds given that both people with ASD in homelessness and busy practitioners in pandemic contexts are hard to reach groups. The COVID-19 lockdown period meant that the DATHI was conducted using online interviews with some informant participants for study 1. Although the online interviewing process complied with the DATHI structure, it cannot be known whether or how this method influenced the informant reports. The prospect of online interview certainly affected the engagement behaviour in study 2 as well as the ASD related difficulties in recruiting this hard to reach group. Nevertheless, samples of this size are common in narrative research and the methodology of study 2 enabled the experiences and perspectives of the three participants to be heard. While the findings from study 2 are not presented as representative of the wider ASD homeless population, these experiences and opinions are widely cited in the literature in this regard.

People with ASD, homeless populations and those who work with them are considered hard to reach research populations and this was evident in our study. This meant that the research methodology needed to be flexible and realistic to this context. Given that no autism screening tool has yet been developed for homeless cohorts or those with co-morbidities, a proxy tool was used for study 1. Like Churchard et al., (2019), we acknowledge that this is a potential limitation of the study, however it did enable the reporting of autism traits by informants who had strong knowledge of the homeless cohort screened. The questionnaire in Study 3 achieved fewer responses than we would have desired; because of COVID related pressures on staff, nevertheless there was an abundance of clear information regarding homeless practitioner ASD knowledge, perceptions of service provision, training needs and recommendations

5.4. Recommendations

5.4.1. Service development (Diagnosis)

Increase investment in diagnostic training, services and supports for ASD in childhood and adolescence. (studies 1 and 2).

Responsibility - HSE/Dept. of Health (DOH)

5.4.2. Research/ Practice development (diagnosis and screening)

- Undertake further validation studies of screening and diagnostic tools for autistic adults
- Develop a range of diagnostic tools to suit varying ASD populations and those with co-morbidities
- Develop basic ASD screening tools that can be used by a range of practitioners (studies 1, 2 and 3).

Responsibility - ASD researchers, psychology departments. Research investment from DOH

5.4.3. Service development/ research (prevention)

Develop evidence informed primary, secondary and tertiary prevention of homelessness among autistic populations (studies 2 and 3).

Responsibility - HSE/Housing agencies/NDA/ autism services. Policy development and ongoing collaboration with relevant services. Research investment

5.4.4. Service development (practice)

- Identify and address barriers preventing autistic homeless people from accessing relevant support services for ASD, addictions, co-morbidities and homelessness.
- Ensure clear pathways to diagnosis and service provision for adults with ASD through appropriate referral pathways.
- Develop cross disciplinary models of support

- Provide specialist services for people with ASD where appropriate; for example mental health services, addiction services (studies 1, 2 and 3)

Responsibility - HSE/ service review and development of autism policy in collaboration with relevant services/ stake holders. Ongoing investment.

5.4.5. Service development (planning and resources)

Increase investment in Autism Friendly Environments in homeless services (studies 2 and 3).

Responsibility - City councils /HSE and homeless services in collaboration with autism services/expertise.

5.4.6. Practice development (education and training)

- Increase homelessness practitioner knowledge of the specific experiences, needs and strengths of people with ASD.
- Support development of relevant practitioner skills and evidenced based approaches and interventions (for example; psychologically informed environments, trauma informed care). (studies 2 and 3).
- Develop continuous training of public service workers and medical professionals related to autism spectrum disorders in order to ensure effective interdisciplinary working (study 3)

Responsibility - Homeless services training (in service and accredited). Collaboration with relevant autism services training agencies/third level education.

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Appendices

Study 1

Appendix 1.1 – Participant Information Leaflet (Keyworkers)

Appendix 1.2 - Consent Form (Key workers)

Appendix 1.3 - Questionnaire 1 – Demographics, health and behaviour history

Appendix 1.4 - Questionnaire 2 - Client characteristics and support needs

Appendix 1.5 - Questionnaire 3 - DSM-5 based ASC traits in homeless individuals semi-structured interview, version 2 (DATHI v2)

Study 2

Appendix 2.1. Participant Information Leaflet (people who identify as homeless and experiencing autism)

Appendix 2.2 Consent Form (people who identify as homeless and experiencing autism)

Appendix 2.3 Interview topic guide.

Study 3

Appendix 3.1 Online Questionnaire for Homelessness Practitioners

Appendix 1.1

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context: A mixed methods study.

Participant Information Leaflet for Keyworkers – Study 1

We would like to invite you to take part in this research project. You should only take part if you would like to, and before you decide whether you want to take part it is important for you to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information.

What is this study about?

This research aims to estimate the percentage of service users who have autistic traits, and to find out more about the particular needs of a homeless person with autistic traits. Autistic Spectrum Disorder is a condition which can lead to a person having many problems coping in everyday life, and we think that there may be clients on your caseload who have this condition but have not received a diagnosis. We will not seek to make full diagnoses, but will rather identify whether or not clients show evidence of autistic traits. If we do find evidence that this is the case it may serve as the basis for better support to be offered to this particular group of clients, and could also lead to further services being developed to meet their needs.

Do I have to take part?

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

What will taking part involve?

If you agree to take part, we will be asking you to take part in interviews with us where we will ask you questions about all the clients you work with. We will ask you how your clients act, how they communicate with you, and about their strengths, needs, and history of homelessness. We will also ask you to complete questionnaires asking similar questions.

We will not at any point ask you for any personally identifiable details of the client, to ensure that we protect their confidentiality. This data will be stored securely and will only be seen by the research team.

What will happen to the information that is collected?

Your responses on the questionnaires will be anonymous and will be analysed together with other keyworker's responses. All written information will be stored securely and will be destroyed five years after the study has been published. All data will be collected and stored in accordance with GDPR. If for any reason you decide to withdraw from the study, all information you provided can be deleted at your request.

Everything that you tell us will be kept confidential; only the research team will have access to what has been said. The recordings will only be listened to by members of the research team, and they will be anonymised and stored on an encrypted drive. They will be deleted once all reliability checks have been completed. Once the project is over, the results will be written-up as part of a report and may be submitted for publication in an academic journal. Reports will not reveal the identity of anyone who took part.

Are there any risks of taking part?

We do not expect your taking part in this study to carry any risk to you.

What are the possible benefits of taking part?

The benefits of this study are that it may help increase and improve service provision for homeless adults in Ireland with autism, as this is a potentially very vulnerable client group with potentially many unmet needs. We will share the results with you and the rest of the team and we hope that you may find this research has some practical benefit in terms of your day-to-day work with clients.

Further information can be sought from Dr. Briege Casey (0831000648/briege.casey@dcu.ie) and Dr. Mary Rose Sweeney (087 9290655 / maryrose.sweeney@dcu.ie) If you have any questions about this study please contact the researchers. If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact. Thank you for considering taking part in this study. This study has been approved by DCU's Research Ethics Committee (Add REC ID Number): You will be given a copy of this information sheet to keep.

Thank you for agreeing to take part in this research.

Appendix 1.2

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Consent Form – Keyworkers Study 1

This form is to be completed by keyworkers to give consent to take part in the research study with Dublin City University, on the prevalence of autistic traits amongst homeless people in their caseload.

Please read the participant information leaflet attached.

Involvement in the research study is voluntary, you may withdraw at any point. No identifying information about any participants will ever be shared or published by the research team. We are committed to protecting people involved in our research however confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is

Participant consent to take part in the research study – please tick where agreed:

☐ I have read the Participant Information Leaflet

☐ I understand the information provided

☐ I have had an opportunity to ask questions and discuss this study (if you have questions, contact Mary Rose Sweeney on 087 9290655 or email maryrose.sweeney@dcu.ie or Briege Casey on 083 1000648, or email briege.casey@dcu.ie

☐ I have received satisfactory answers to all my questions

☐ I am aware that I will complete questionnaires about my caseload as part of this research

Signature:

____

I have read and understood the information in this form.

My questions and concerns have been answered by the researchers. Therefore, I consent to take part in this research project

Keyworker Signature: _______________________________________

Name in Block Capitals: _______________________________________

Date:____

Researcher's signature: ____

Appendix 1.3

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Questionnaire 1 – Demographics, health and behaviour history

DEMOGRAPHIC INFORMATION

Gender: ☐ Male ☐ Female ☐ Transgender*

*If Transgender please state gender assigned at birth:

Ethnicity: ☐ White Irish ☐ Asian or Asian British ☐ Middle Eastern

☐ Black or Black British ☐ Gypsy/Romany/Traveller ☐ Mixed Ethnicity

Age:

NATURE OF HOMELESSNESS

Where is this client currently staying?

☐ Street homeless

☐ B & B, emergency or temporary accommodation

☐ Independent accommodation

☐ Semi-independent accommodation

☐ Prison

☐ Hostel

☐ Friends and family

☐ Disappeared (not seen for 90 days)

☐ Other, please state:

How long has the client been homeless for:

MENTAL HEALTH

	Diagnosed	**Suspected**	**No**	**Don't know**
Psychosis (e.g. paranoia, hallucinations, hearing voices delusions)	☐	☐	☒	☐
Depression	☐	☐	☒	☐
Anxiety Disorder (e.g. Social Anxiety, Panic Disorder, Generalized Anxiety Disorder)	☐	☐	☒	☐
Obsessive Compulsive Disorder (OCD)	☐	☐	☒	☐
Post-Traumatic Stress Disorder	☐	☐	☒	☐
Personality Disorder	☐	☐	☒	☐
Eating Disorder	☐	☐	☒	☐
Bipolar Disorder	☐	☐	☒	☐
Other (please state):	☐	☐		

	Yes	**Suspected**	**No**	**Don't know**
Has the client experienced any traumatic events (i.e. exposure to actual or threatened death, serious injury or sexual violation or witnessed a traumatic event)	☐	☐	☒	☐

Has the client been prescribed medication for their mental health? ☐ Current ☐ Past ☐ No ☐ Don't know
If yes and known, please state:

DRUG /ALCOHOL USE			
	Type	Frequency of use	Amount used
Primary drug			
Secondary drug			
Other substances used			
Prescribed Methadone/Subutex			
Prescription medication			
Alcohol			
Tobacco Smoking			

RISK TO SELF	**Current**	**Past**	**Recurrent/persistent issue (i.e. more than one incidence or period)**
Suicidal thoughts	☐	☐	
Suicide attempts	☐	☐	
Self-harm	☐	☐	
Self-neglect	☐	☐	

Not taking prescribed medication	☐	☐	☐
Not making or attending a medical appointment when objectively in need	☐	☐	☐
RISK FROM OTHERS	**Current**	**Past**	**Recurrent /persistent issue**
Violence / aggression	☐	☐	☐
Financial exploitation	☐	☐	☐
Psychological abuse/bullying	☐	☐	☐
Sexual abuse/exploitation	☐	☐	☐
RISK TO OTHERS	**Current**	**Past**	
Violence / aggression	☐	☐	
Financial exploitation	☐	☐	
Psychological abuse/bullying	☐	☐	
Sexual abuse/exploitation	☐	☐	
Arson	☐	☐	

Over the past 3 months has the client displayed any of the following behaviours in any context (tick all that apply):

☐ Physical aggression to other

☐ Destruction of clothing, belongings or property

☐ Over-active, paces up and down, does not sit still

☐ Seeks attention, pesters staff and others

☐ Self-injury, head banging, picking of sores

☐ Screams or makes other disturbing noises

☐ Argumentative or verbal abuse

☐ Scatters or throws objects around

☐ Antisocial behaviour(e.g. steals, lies or bullies others)

☐ Sexually inappropriate behaviour

☐ Unusual or restrictive eating behaviour e.g. avoidance of certain foods due to texture

(**Not Applicable)**

DISABILITY / DEVELOPMENTAL ISSUES / PHYSICAL HEALTH

	Diagnosed	**Suspected**	**No**	**Don't know**
Autism or Asperger's Syndrome	☐	☐	☒	☐
Attention Deficit Hyperactivity Disorder (ADHD)	☐	☐	☒	☐
Diagnosed learning disability (aka intellectual disability)	☐	☐	☒	☐
Known learning difficulty (please tick if known)	☐ Dyslexia		☐ Dyscalculia	
	Yes	**Suspected**	**No**	**Don't know**
Previous head injury	☐	☐	☒	☐

Does the client have any physical health problems (e.g. epilepsy, diabetes, asthma, COPD, previous stroke)? ☐ Yes ☐ No ☐ Don't know
If yes, please state all:

PAST HISTORY	
Aged 18 and under, did the client have contact with any of the following services (tick all that apply):	
☐ Adoption or foster care services	☐ Attended special school
☐ Local authority care	☐ Received educational support at school
☐ Young offenders institute	☐ Had a statement or equivalent at school
☐ Child and adolescent mental health services	☐ Don't know **(Not Applicable)**
☐ Social services	☐ Other, please state:
RELATIONSHIP TO SERVICES	
Length of time you have known the client:	
Frequency of your contact with this client:	Key working sessions –
Average length of time spent with this client at each session:	1 Hour
How would you rate the quality of rapport with this client on a scale of 1-10 (1=poor, 10 =good) please tick: ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10	

LINKS TO OTHER AGENCIES (please tick all that currently apply):	
☐ Registered GP	☐ Social worker
☐ Drug/alcohol worker	☐ Daycentre
☐ Advice service (e.g. CAB)	☐ Solicitor
☐ Community Mental Health Team (CMHT)	☐ Other please state:

How would you describe the client's history of homelessness? (Please give a rough timeline with type of accommodation and include any periods of prison or disappearance etc.)

Appendix 1.4

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Questionnaire 2 - Client characteristics and support needs

A. Characteristics of homelessness

1. Before the client became homeless, what was the nature of their circumstances?
    - Employment, housing, social network, contact with services, were they a care leaver
2. What led to the client becoming homeless?
3. What are the client's current relationships like?
    - Do they have friends, family, partner, children, acquaintances?
    - How regular is the contact?
    - What is the client's view of current relationships?
    - Is the client seeking relationships?
4. a) What has got in the way of this client maintaining stable accommodation or accessing accommodation?
    - I.e Breakdowns (abandonment or eviction)
    - Rejection of accommodation offers
    - Were sensory needs involved (e.g. noise levels in hostel), difficulties engaging with others, managing with change

b) Do the client's views of the breakdowns differ from yours? If so, what is their view?

5. How does the client view themselves and their situation?
    - Do they view themselves as homeless
    - Do they see this as a problem
    - How do they view other homeless people

B. Skills and obstacles for independent living

1. What are the client's goals, aims or priorities?
    - E.g. with respects to accommodation, relationships, employment, money, other
2. What are the client's strengths?
3. How does the client manage with practical challenges e.g. paying bills, accessing benefits, completing forms?
    - How do they sustain themselves/make money?
4. What is stopping this person from making progress?
    - E.g. living independently
    - Pros and cons of living independently
    - Stages of change

C. <u>Relationship with services and staff</u>

1. If there have been any difficulties with establishing or maintaining rapport, what would you describe as the main issues?
2. How do you generally feel after an interaction with this client?
3. How does this person manage with building new relationships, maintaining relationships and relationships ending?
4. What is the client's relationship to services like?
    - Do they seek help? Dependent on services? Avoidant?
    - Beliefs/expectations about help/professionals/services?
    - How do they respond to offers of help?
    - What help does the client want from the keyworker?

Appendix 1.5

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context: A mixed methods study.

DSM-5 based ASC traits in homeless individuals semi-structured interview, version 2 (DATHI v2)

Rubric

Autistic Spectrum Condition (ASC) is a condition which manifests in a wide variety of ways, and two people with ASC may have completely different presentations. This questionnaire does not therefore provide a checklist of particular behaviours, as the presence of a behaviour is not in itself diagnostic of ASC. It rather lists a number of behaviours, and asks that the researcher consider with keyworkers whether the ways these behaviours manifest is consistent with a presentation of ASC. Throughout researchers should proceed according to the following process:

1. Is the behaviour manifested by the client?
2. If yes, what form does the behaviour take?
3. Is the behaviour consistent across different settings/contexts?
4. Why does the keyworker think the behaviour is being manifested? Are there any obvious reasons why the client acts in this way?

[rubric continues on next page]

Classification	Criteria
Present	• Behaviour(s) associated with trait clearly observed with examples given. • Each behaviour is seen across multiple contexts OR Behaviour seen in one context very clearly meets ASC criteria. • The behaviour is not attributable to other causes. • Not every behaviour has to be present for this to be met, and a single behaviour may be sufficient to give this classification if it very clearly matches DSM-5 criteria (ie. One clearly evident fixated interest would be sufficient to meet criterion B3).
Possibly present	• Meeting any of the following criteria is sufficient reason to give this overall classification: o Behaviour(s) associated with trait observed, but it is unclear whether they fully match up with DSM-5 criteria. o A single behaviour likely to be consistent with ASC is observed, but no other ASC-related behaviours are observed (however also consider the last bullet point from the box above when deciding whether or not this is applicable). o Behaviour(s) associated with trait observed, but they do not reliably appear across multiple contexts. o Aspects of trait observed and may be better explained by other cause, but this is unclear (ie. Is it anxiety or ASC?).
Not present	• Trait not observed, is clearly attributable to other causes (e.g. anxiety, psychosis), or only bears superficial resemblance to DSM-5 criteria (e.g. Unfriendly when drunk).
Insufficient information to classify	• Client is so poorly known to services that any attempt to match their behaviour to criterion would be a guess.

Additional guidelines for decision making on individual items

Where the scorer thinks a score on an item falls between classifications (i.e. between 'Not present' and 'Possibly present', or between 'Possibly present' and 'Present') the following guidelines should be followed:

- For Section A (items A1-A3) the scorer should score down
  - E.g. If the scorer thinks the score falls between 'Present' and 'Possibly present' the scorer should rate the item as 'Possibly present'. Similarly if the scorer

  thinks the item falls between ‘Not present’ and ‘Possibly present’ they should rate the item as ‘Not present’.

- For Section B (items B1-B4) the scorer should score up
  - E.g. if the score falls between ‘Present’ and ‘Possibly present’ the scorer should rate the item as ‘Present’. If the scorer thinks the item falls between ‘Not present’ and ‘Possibly present’ they should rate the item as ‘Possibly present’.
  - The only exception to this is B2 – prompt around difficulty coping with change. It is evident that the general homeless population for different reasons struggle with change. There should be clear examples here of previous difficulties coping with change (e.g. change in the way benefits are given) rather than general fear of change (e.g. refusing accommodation due to avoidance of change)

[rubric continues on following page]

Guidelines for 'Overall classification'

The following guidelines should be followed to give an overall classification of the presence of autistic traits:

Classification	Criteria
Present	**Section A:** • 3 items = present OR • 2 items = present AND 1 item = possibly present AND **Section B:** • At least 2 items = present OR • 1 item = present AND at least 2 items = possibly present
Possibly present	**Section A:** • All items at least = possibly present AND **Section B:** • At least 2 items = at least possibly present
Not present	• Does not meet criteria for 'Possibly present'
Insufficient information to classify	• Client is so poorly known to services that any attempt to match their behaviour to criteria would be a guess (this same classification will be seen on individual items).

The above guidelines should normally be followed to make the overall classification. However, in some cases the general clinical presentation and/or contextual information may raise doubts about the accuracy of the overall classification. In the case the overall classification may be changed, but this should only happen rarely and after careful consideration. Examples of when this might occur include:

- An individual whose overall presentation appears markedly autistic, but who has not quite met criteria for 'Present' and has instead been put in the 'Possibly present' category. In this case it would be appropriate to re-categorise them into 'Present'.
- An individual who has met criteria for 'Present', but it is very unclear what the nature and cause of their autistic traits is. This might be seen in a very complex clinical presentation with other confounding factors such as a high level of substance misuse. In this case it would therefore be more appropriate to put them in the 'Possibly present' category.

Client ID -

Criterion	Prompt questions	Answers	Trait present?
A1: Deficits in social-emotional reciprocity	Is the client able to initiate social contact? • Specific prompts: o Appears completely absent o Absence of greetings o Does so in a strange manner Does the client respond to social interactions in an odd fashion? • Specific prompts: o Awkward o Overly blunt o Hostile o Response to smile o Overfriendliness o Gives too much information Can the client engage in back-and-forth conversation? • Specific prompts: o Monosyllabic replies / only limited responses o Responds only to questions o Tangential responses o Monopolises conversation o Overly repetitive in same conversation Can the client talk about their feelings, and if so how do they talk about them? • Specific prompts:		o Present o Possibly present o Not present o Insufficient information to classify

Criterion	Prompt questions	Answers	Trait present?
	o Completely immersed o Only superficial or stereotyped descriptions o Possible to explore further?		

A2: Deficits in nonverbal communicative behaviors used for social interaction	What is the client's eye contact like? • Specific prompts: o Absent o Fixed gaze What are the client's facial expressions like? • Specific prompts: o Absent o Limited range o Smile but nothing else o Could you guess how the client was feeling from their facial expression? Does the client use and understand body language and gestures? • Specific prompts: o Pointing o Nodding o Shaking the head o Inexpressive posture: stiff / rigid upper body o Absence of demonstrative gestures o Exaggerated / odd gestures Does the client recognise unspoken cues when you are interacting with them?		o Present o Possibly present o Not present o Insufficient information to classify

	• Specific prompts: o eg. Standing up at the end of a meeting to indicate the conversation is at an end o Responding to non-verbal instructions. Eg. shake of the head when you don't want someone to do something When talking to others people typically coordinate their tone of voice, facial expressions, eye contact, gestures and body language with what they're saying. Does the client do this?	.	

A3: Deficits in developing, maintaining, and understanding relationships	Does the client adjust their behaviour depending on who they are around? Does the client notice and understand the impact their behaviour has on others? • Specific prompts: o Rudeness o Losing temper o Being friendly / giving compliments o Oversharing Does the client show an intuitive understanding of social situations? How successful has the client been at forming and maintaining friendships? Has the client been able to forms relationships with other individuals they come into contact with, such as hostel workers and staff?		o Present o Possibly present o Not present o Insufficient information to classify

	• Specific prompts: o One sided friendships? Is the client interested in making friends? Does the client show any interest in other people? • Specific prompts: o Enjoys small talk / socialising for its own sake (beyond meeting wants/needs) o Asking people how they are o Asking people what they are up to o Remember what people have told them in previous conversations?		

B1: Stereotyped or repetitive motor movements, use of objects, or speech	Does the client show any repetitive movements? Does the client show any unusual hand mannerisms? Does the client repeat the same phrases many times? With regards to the sound of the client's voice, is their intonation unchanging / monotonous? Is the way the client speaks especially formal or stilted? Does the client use words they have made up themselves in conversation? Does the client repeat words you or someone else has said in a socially inappropriate manner?		○ Present ○ Possibly present ○ Not present ○ Insufficient information to classify

B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behaviour	Does the client have any unusual routines? • Specific prompt: o Very bound to this routine? o How do they cope if routine breaks down? (ie. Changing appointment time) Does the client find it unusually difficult to cope with change and new activities? • Specific prompt: o Even small change o Even if change / new activity is something others see as positive o Consider many types of behaviour ie. Food, greeting rituals Does the client show any ritualized or compulsive behaviour, either verbal or non-verbal? • Specific prompt: o Organisation of belongings o Routes taken o Sleep sites o Patterns of touching o Mentioning dates / pieces of information o Strong need to get to end of what they're saying		o Present o Possibly present o Not present o Insufficient information to classify

B3: Highly restricted, fixated interests that are abnormal in intensity or focus	Does the client show an excessive interest in particular topics or objects? • Specific prompt: o Keeps on wanting to talk about a particular topic? o Fixation on an issue, not just a hobby? Does the client have any very focussed interests? • Specific prompt: o Collecting an entire set of a particular item		o Present o Possibly present o Not present o Insufficient information to classify

B4: Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment	Does the client show an odd response or seem unduly sensitive to any sensations? Ie. Sight, sound, taste, touch, smell • Specific prompts o Loud noises / wears ear protectors? o Bright lights o General levels of stimulation (eg. daycentre, canteen) o Refusing to wear certain clothes because of the feel of the material o Clothes need to be a certain level of tightness / looseness, have a favourite bit of clothing o Commenting on smells that most people would not notice o Eating Does the client have a particularly strong interest in any sensory stimuli? Ie. Sight, sound, taste, touch, smell Does the client appear to find any everyday sensory stimuli painful or distressing? Does the client appear under-reactive to certain sensations? • Specific prompts o Pain ie. injuries going untreated o Cold / heat		o Present o Possibly present o Not present o Insufficient information to classify

Do any of the symptoms talked about above cause significant impairment in the client's current functioning? If so, which ones?

Is there anything else you have noticed about the client which you think might be relevant to what we have been discussing today?

Appendix 2.1

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Participant Information Leaflet – Study 2

Autism is a developmental disability that can affect how one relates to, and communicates with other people. Common presenting features in Autism can be - difficulties with communication, socializing, repetitive behaviours and a heightened sensory perception of smells, noise, colour, bustling places etc.

Autistic adults are at increased risk of homelessness due to the association between Autism spectrum disorders poor socio-economic outcomes and discrimination. No previous research has examined the prevalence of autism in homelessness. This research will explore your experiences of being homeless as an autistic person and whether your autism specific needs are being met by any support services.

You are invited to take part in an interview about your experiences of being on the Autism spectrum and homeless. The interview will be audio recorded and then transcribed and stored on a computer. No personal identifiers will be used. Nobody will be able to identify that it was you who took part in the interview.

The interviews will be conducted by researchers from DCU in a location and time that is convenient for you.

If you would like to take part in the research or hear more about the study please contact the research team Dr. Briege Casey (0831000648/briege.casey@dcu.ie) and Dr. Mary Rose Sweeney (087 9290655/maryrose.sweeney@dcu.ie.

Appendix 2.2

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Consent Form for participants who identify as homeless and experiencing autism

Please read the participant information leaflet attached.

Involvement in the research study is voluntary, you may withdraw at any point. No identifying information about any participants will ever be shared or published by the research team. We are committed to protecting people involved in our research however confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law - i.e., it is possible

Participant assent and parent/guardian consent to take part in the research study – please tick where agreed:

☐ I have read the Participant Information Leaflet (or have had read to me)

☐ I understand the information provided

☐ I have had an opportunity to ask questions and discuss this study (if you have questions, contact Mary Rose Sweeney on 087 9290655 or email maryrose.sweeney@dcu.ie or Briege Casey on 083 1000648, or email briege.casey@dcu.ie

☐ I have received satisfactory answers to all my questions

☐ I am aware that I will complete questionnaires about my caseload as part of this research

I have read and understood the information in this form.

My questions and concerns have been answered by the researchers. Therefore, I consent to take part in this research project

Signature: ____

or mark X to indicate agreement to participate

(If no signature is provided the "X" must be witnessed by 2 members of the research team)

Date:____

Researcher's signature: ____

Appendix 2.3

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Interview Topic Guide

1. Tell me about your experiences of being autistic and homeless

2. Do you think being autistic contributed to you becoming homeless? If so in what ways?

3. What challenges do you experience as a result of being autistic and homeless?

4. What autism specific supports do you need?

5. Describe the level and nature of support you receive(d) for your autism related needs while homeless.

6. Which services/supports were useful and where could improvements be made in relation to your own case?

7. What recommendations would you make for effective support of people with autism what are at risk of or experiencing homelessness?

Appendix 3.1

Adult autism in homelessness: prevalence, experiences and support needs in an Irish context – a mixed methods study

Online Questionnaire for Homelessness Practitioners

Thank you for taking the time to complete this questionnaire. Your responses will help us to understand the level of knowledge and confidence of Irish keyworkers in working with adult autistic clients in homeless service contexts. This is important information to gather as recent research indicates that autism is more common among homeless adult populations, yet it is often not recognised and undiagnosed. In the questionnaire you will be asked some general questions regarding your age, gender and work experience. This will be followed by some questions regarding your knowledge about autism. We also want to find out about your perceptions of your training and support needs in this area. This is not a test so don't worry if you are not sure about some of the answers. All responses are anonymous and confidential and cannot be traced back to you or your service. You are also free to not respond to particular questions or sections in the questionnaire. This research study has been approved by DCU Research Ethics committee; DCU REC2019_124. In the questionnaire, the term 'autism' refers to all types of autism including Asperger syndrome.

Please tick this box to confirm that you have read and understood this information and that you consent to participate in this questionnaire ☐

Section 1: About Me

1.1: Age (Please tick)

17-25 years	
25-35 years	
35 -50 years	
50+ years	

1.2: Gender (Please tick)

Male	
Female	
Other (specify)	
Other (not specified)	

1.3: Length of time working in homelessness services (Please tick)

0-5Years	
5-10 years	
10 -20 years	
20+ years	

1.4: What was your role for most of that time? (Please tick)

Project worker	
Key worker	
Case manager	
Manager	
Other (please specify)	

1.5. Have you had any formal training in autism? Y ☐ N ☐

1.5.1: If yes give details and the date(s) training was undertaken

1.6: Do you know anybody in your personal or working life who has a diagnosis of autism? Tick all that apply.

Myself	
Friend	
Close Relative/Partner	
Client/Service User	
Colleague	
Other	

1.7: How would you rate your level of knowledge regarding autism? Tick the answer that applies

Poor; I know very little about autism	
Average – good. I have some general knowledge concerning autism	
Very good – I have some specialised knowledge and skills concerning the needs of autistic people.	

Section 2: About Autism

The next questions ask what you know about autism and what you think people with autism are like. Autism here means all types of Autism including Asperger syndrome. This is not a test and different people will have different levels of knowledge.

2.1: Autism is (tick any/all that apply)

A developmental disability	
A mental illness	
An intellectual disability	
A different way of interpreting the world and processing communication	

2.2: What behaviours might lead to you to believe that a person may have autism?

2.3: When you think of someone with autism, what (if any) do you think are their main strengths?

List/Comment	
None	
Don't Know	

2.4: When you think of someone with autism, what (if any) do you think are their main difficulties?

List/Comment	
None	
Don't Know	

2.5: How common do you think Autism is in Ireland today?

1 in 10 people	
1 in 100 people	
1 in 1000 people	
2 in 10,000 people	
Don't know	

2.6: What percentage of people with autism also experience/exhibit the following?

	None	Under 20%	20% - 50%	50% - 70%	Over 70%
Intellectual disability					
Mental health problems					
Substance use					
Behaviours that challenge					
Special ability eg, maths, music, art					

2.8: How much do you agree or disagree with the following statements about the **causes** of autism?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don’t know
Autism is caused by vaccines like MMR						
Autism is caused by something in the environment						
Autism can be inherited						
Autism is caused by poor parenting skills						
Other/Different cause (specify)						

2.9: How much do you agree or disagree with the following statements about the **treatment** of Autism?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don’t know
There are drug treatments that are effective in helping people with Autism						
There are behavioural interventions that are effective in helping people with Autism						
There are other non-drug related therapies and supports that are effective in helping people with Autism						
There is nothing that can help with Autism						
People with Autism do not need help						

2.10: How much do you agree or disagree with the following statements about autism.

	Strongly Agree	Agree	Neither agree nor Disagree	Disagree	Strongly Disagree	Don't know
Autism is a life-long disability and you can do nothing about it						
When someone has autism their choices are not respected enough						
It is better for people with severe Autism if they are cared for in a residential unit						
It is better for families of people with severe Autism if they are cared for in a residential unit						

Section 3: Autism and homelessness

3.1: As a practitioner in homeless services, what would be your own estimate of adult homeless clients who demonstrate autistic behaviours?

0% -5%	
5% - 15%	
15% - 30%	
30% -60%	
Over 60%	
Don't know/Would prefer not to estimate	

3.2: Entering and exiting homelessness. How much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither agree nor Disagree	Disagree	Strongly Disagree	Don't know
People with Autism are more likely to be homeless than people without Autism						
People with autism need special consideration when it comes to housing allocation						
People with autism find it more difficult to exit homelessness than people without autism						

3.3: In relation to people with autism, what aspects might affect the task of achieving and maintaining a suitable home?

3.4: We are interested in your perceptions of your own knowledge and skills when working with autistic people. How much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither agree nor Disagree	Disagree	Strongly Disagree	Don’t know
I feel confident about identifying autistic behaviours as part of client assessment						
If I identify autistic behaviours in a client who does not have an autism diagnosis, I would know what action to take next						
I feel that I have enough knowledge about the specific needs of autistic people to be able to work effectively with them in my service						
I need to make my communication skills more sensitive to the needs of people with autism						
I am satisfied with the training that I have received regarding working with autistic people in my service						
I have received little or no formal training specifically related to autism						

	Strongly Agree	Agree	Neither agree nor Disagree	Disagree	Strongly Disagree	Don't know
I learned most of what I know about autism through personal experience						
I learned most of what I know about autism through professional working experience						
I am aware of services and supports that I can avail of/refer clients to for autism support						
I would like to avail of training specifically related to understanding and supporting the needs of autistic people in homeless contexts						

3.5: In the comment box below please tell us which aspects (if any) of supporting clients with autism do you find most challenging and why

3.6: In your opinion, what is the level of awareness and support for autistic people in your service? Please tick the relevant answer

Poor level of awareness and support in relation to autism	
Some awareness among staff but little specific support in place for clients who have autism/ autism behaviours	
Staff are aware of and use evidence based practice in working with all clients who have autism/autism behaviours.	
Staff and the service environment are well prepared to accommodate a range of developmental /communication issues, including autism, among all clients	

3.7: Are there any specific interventions or arrangements for people with autism in your service? Please tick Y ☐ N ☐

3.7.1 If yes, please describe

3.8: Do you think homeless services in Ireland make adequate provision for people with autism?

Y ☐ N ☐

3.8.1: If yes, in what ways? If no, what else could homeless services do to support people with autism?

3.9: What is your understanding of the term ‘Autism Friendly?’

3.10: In relation to specific autism training for staff working in homeless services, how much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither agree nor Disagree	Disagree	Strongly Disagree	Don’t know
Training is not required – general sensitivity to needs of homeless clients is enough						
Training should be mandatory						
It should be small group training						
Training should be online						
Training should be in lecture format						
All information required could be contained in a guidebook						

3.11: Any other comments, suggestions or recommendations?

Thank you for taking the time to complete this questionnaire